Summary

Sweden is still in the midst of a major, widespread crisis. The coronavirus has made its way across the world, causing illness and death. The pandemic has also led to other far-reaching consequences for individuals and for the society at large, the scope of which we cannot yet fully comprehend. In parallel with the public debate on how this emergency is being handled, a number of countries have now embarked on a process of more long-term reflection and self-scrutiny.

At the beginning of December 2020, more than 7,000 people have died of COVID-19 in Sweden.[1] Of these, almost 90 percent were aged 70 years or older. Half of them were living in a long-term residential care facility (which encompasses nursing homes, care homes and sheltered housing), and just under 30 percent were receiving home help services. The large share of deaths among fragile elderly people is in line with observations from many other countries. We find it most likely that the single most important factor behind the major outbreaks and the high number of deaths in residential care is the overall spread of the virus in the society.
The observation that the spread of infection in residential care follows similar patterns in several countries seems explicable. The OECD states that the pandemic has highlighted a part of society that is undervalued and under-resourced. The WHO also points to a number of common structural problems that have contributed to severe implication of the pandemic on people in residential care.

However, not all countries have been equally hard hit, neither within nor outside of residential care. There are also major regional

differences within countries, and between different residential care homes. In this report we set out, in our view, the most important causes of the major spread of the virus and the high number

[1] This includes all deaths where COVID-19 was reported on the death certificate, either as the underlying cause of death or as a contributing cause.

of fatalities among the elderly population in Sweden. However, based on currently available evidence, we are not yet able to assess the relative importance of the different causes of the high numbers of cases and deaths in residential care and among those with home help services. Nor do we have data to evaluate some of the measures taken without a more comprehensive analysis of the spread of the virus in society in general, or an assessment of the more general handling of the pandemic. We will therefore return to these questions in later reports.

The strategy of protecting the elderly has failed

The Commission's overarching assessment can be simply summed up as follows: apart from the general spread of the virus in society, the factor that has had the greatest impact on the number of cases of illness and deaths from COVID-19 in Swedish residential care is structural shortcomings that have been well-known for a long time. These shortcomings have led to residential care being unprepared and ill-equipped to handle a pandemic. Staff employed in the elderly care sector were largely left by themselves to tackle the crisis.

In Spring 2020, the Government and central government agencies put in place a number of measures to reduce the risk of spread of the virus in residential care (which in Sweden is carried out at the local government level). According to our overarching assessment, these measures were late, despite early information that older people were particularly vulnerable. We judge that the measures were also insufficient in several respects.

The view of the Commission is that the ambition of Sweden's overarching strategy to specifically protect the elderly population was and is correct. Although Sweden, in comparison with other countries, does not stand out with a high share of deaths in residential care, it is nevertheless clear that, so far, this part of the strategy has failed.

Preparedness of the elderly care sector – structural shortcomings

Fragmented organisation

In Sweden, crisis management is built on the principle of responsibility. This means that the party responsible for a particular activity under normal circumstances, is also responsible for that activity in a crisis situation. This is a simple principle in theory, but the more people who share the responsibility, the harder it becomes to make the system as a whole work well in practice. In Sweden, responsibility for the health and care of the elderly population is decentralized to local government, which means that it is divided between 21 regions and 290 municipalities. Many regions and municipalities also have a large number of private providers. On top of this, there are the central government agencies with a national responsibility in these areas.

When the spread of virus broke out, there was no overview at national level of the municipalities' preparedness to tackle a pandemic. The central government agencies concerned had not sought this information sufficiently early on, or to a sufficient extent, and if they had done so, it had not reached all the way to the parties involved. In the decentralized – and non-integrated – Swedish system the regional councils are tasked with the responsibility of health care, while the elderly care is mainly the task of the municipalities. However, it should be noted that the municipalities to a limited extent holds the responsibility for the health care in elderly care. There was also a lack of established channels between, for example, the National Board of Health and Welfare and the municipal healthcare system similar to the channels in place between the Board and the regional healthcare system.

When it comes to the division of responsibility between regions and municipalities, it has been asserted for many decades that these divisions lead to significant problems. In the past two decades, different studies and inquiries have shed light on the consequences that these shortcomings in coordination might have. The regions' responsibility for physicians and the municipalities' responsibility for elderly care, illustrate the problems that arise when two principals simultaneously share responsibility. The National Board of Health and Welfare and the Health and Social Care Inspectorate, have drawn attention to shortcomings in the lack of integrated care.

Even in normal times, the shared responsibility between different principals and a number of different actors presupposes good, trusting and continuous collaboration. In a pandemic – with demands for rapid prioritisation and knowledge transfer, and with a lack of necessary equipment – this division of responsibility makes even higher demands in terms of well-functioning organisations, coordination and collaboration.

A part of the Commission's mandate for its future work is to evaluate how the crisis management principle of responsibility has worked during the crisis, and to propose measures that derive from these observations. In our view, as long as the current principle of responsibility applies, it is of utmost importance that coordination and collaboration between municipalities and regions work well, especially for tackling a crisis such as a pandemic. There is a need for instruments and established institutional channels that ensure continuous operational coordination between regions and municipalities. All parties involved need to safeguard the whole system and invest in sufficient resources. This is likely to require overarching changes in governance of elderly care, including medical care.

The lack of patient-centred, integrated patient medical records is a severe threat to the safety of patients. The regions and the municipalities must take action to put in place systems for integrated medical records.

Need for higher staffing levels, greater expertise and reasonable working conditions

Major initiatives have been carried out during the pandemic to provide the elderly population with as good healthcare and social care as possible in the prevailing circumstances. Many employees have worked under extreme pressure, experienced fear and exposed themselves and their families to significant risk. They have still done their utmost to meet the needs of recipients of healthcare and elderly care and to keep services running. Many managers and crisis management teams across Sweden have worked hard to find solutions in an unprecedentedly tough situation.

At the same time, the Commission notes that, in addition to non-integrated responsibility for health and medical care, elderly care suffers from clear, major structural problems that the pandemic has

exposed. The OECD and the WHO have described elderly care as an under-resourced part of society that is staffed by an undervalued team of professionals, and Sweden is no exception.

The structural problems of elderly care that have been well-known for a long time have to be addressed. It is necessary to increase the level of ambition and to raise the status of and the attractiveness of the caring professions to provide good quality healthcare and social care in a crisis such as the pandemic.

The Commission considers that the Swedish parliament and the Government must review what should be considered sufficient staffing rates in long-term residential care and in home help services, not least in terms of the care and treatment of people with dementia.

The employers must also better facilitate leadership by reviewing leadership structures and organisations such that managers are to be responsible for a much lower number of employees. Furthermore, the employers must improve employment security and staff continuity in elderly care and sharply reduce the proportion of staff on zero-hours contracts. While it is hard to completely avoid using employees on zero-hours contracts who can be called in at short notice when required in as staff-intensive a sector as healthcare and elderly care, the proportion of staff on such contracts must be significantly reduced.

Regarding the level of expertise in elderly care, the composition of workers from different professions clearly differs between the Nordic countries. Unfortunately, Sweden does not stand out in a positive sense in this respect. Despite increased medical needs among recipients of elderly care in Sweden, the share of medically trained personnel is generally low.

The view of the Commission is that medical expertise in elderly care needs to be increased. This could be achieved, for example, by introducing a requirement on minimum training for different professional categories, and, in conjunction with this, considering the need for extra training initiatives. As a general rule, nursing skills should be available in all residential care facilities, round the clock, seven days a week. Firstly, this is essential for access to medical interventions in the form of drips and oxygen, but also to ensure that other staff are able to obtain support and guidance in both care and in medical treatment. Furthermore, the municipalities must

carry out language training initiatives for care staff who lack sufficient language skills.

The vital increase in ambitions may demand the support of Government initiatives.

Inadequate regulatory framework

Many measures to prevent the spread of the virus in residential care for older people contradict the normative principles on which Swedish elder care is based. It is, at best, uncertain whether the legislation in place would allow for all the measures needed in these settings. Among other things, this involves arranging cohort care, i.e. where one or more people infected with the virus are cared for separately by staff who only work with these residents.

The view of the Commission is that, in an exceptional situation, a provider of health and elderly care must be able to take the restrictive measures required to effectively provide protection from the virus. However, it is evident that such restrictions on the freedom and rights of the individual must have legislative backing. It is not reasonable to delegate these difficult decisions to local politicians and employees.

The current regulatory framework does not go far enough, nor is it clear enough. The legislator must therefore ensure that there are legal opportunities in elderly care to take the measures needed to protect recipients of social care in a pandemic and in other extraordinary crisis situations.

The possibility for municipalities to employ physicians and to access to medical equipment

The municipalities are one of the principals of healthcare for older people. The regions are however responsible for medical care provided by physicians. This responsibility may not be transferred to the municipalities. In principle, this presents an obstacle for municipalities in that they are unable to employ physicians for elderly care. This makes elderly care dependent on the regions' priorities for the kinds of medical assessments provided by physicians. It also means that in principle, physicians cannot be involved in the

planning of healthcare within the municipality not even in the crisis management that the municipality has to perform during a pandemic. No equivalent division in responsibility between different principals exists in our neighbouring countries.

The view of the Commission is that the categorical division between municipality and region in terms of responsibility for physicians does not appear to be an appropriate solution in a normal situation, and especially not in a crisis in which every step in the decision-making process and interface constitutes an inherent vulnerability. It is therefore the view of the Commission that it ought to be possible for municipalities to employ physicians.

The Commission further believes that all residential care for the older population should have the medical equipment necessary for medical interventions and good palliative care to take place on site. This includes apparatus for providing oxygen and nutrient solution. An apparent reason for this is that it would enable the resident to access such interventions without the potential stress of a hospital transport and a hospital stay.

Specific decisions and measures – late and sometimes insufficient

Attention was only paid to elderly care at a later stage

Protecting the elderly population became an objective at an early stage of the pandemic. However, it took far too long before attention was paid to the specific problems and shortcomings in municipal elderly care.

The Commission can confirm that the main focus of the responsible government agencies in the early stages of the pandemic was on regional healthcare capacity. We believe that it was reasonable to prioritise the capacity of healthcare to treat serious cases of COVID-19 and to provide recommendations to the public aimed at limiting the spread of the virus. Still, it appears blameworthy that attention was not drawn to the conditions in residential care for consistently frail older people earlier, seeing as it was known that the consequences of infection were particularly severe in this group. The Public Health Agency of Sweden and the National Board of Health and Welfare should have immediately placed more emphasis on conditions in

residential care for older persons. Our assessment is that these central government agencies did not have an adequate overview of the problems and deficiencies in municipal elderly care. This meant that guidance on measures in elderly care was delayed.

Problems with personal protective equipment

Access to personal protective equipment (PPE) was remarkably poor in the initial stage of the pandemic. As early as February 4–6, both the Swedish Civil Contingencies Agency (MSB) and the National Board of Health and Welfare identified a risk that a deficiency in PPE could arise. However, it was not until early April, long after the virus had entered residential care for older people, that the National Board of Health and Welfare began to form an overview of the situation in the municipalities, via the county administrative boards which are regional government agencies.

The view of the Commission is that it took an unreasonably long time to clarify and define the need for PPE in elderly care. Given the large number of municipalities and care providers in Sweden, channels for reporting such needs should already have been established or have been rapidly organised. However, these questions will be further examined in a later report. The same applies to issues regarding emergency stock, priorities in the event of a shortage and procurement or repurposing of production.

The question of which protective equipment was to be used when working with recipients of care who were suspected or confirmed to be infected with the virus was long disputed, and conflicts arose in several workplaces. The handling of the question of PPE in elderly care by the responsible agencies gave rise to a lack of clarity as to which PPE was appropriate. According to the Commission, it is reasonable to assume that the absence of clear guidelines and the obvious lack of PPE in elderly care contributed to the spread of the virus there. There should have been early and consistent guidelines conveyed by both the Swedish Work Environment Authority and the Public Health Agency of Sweden surrounding the use of PPE. Alternatively, it should have been stated how the objectives of protecting staff and preventing the spread of the virus were to be weighed against each other.

The late introduction of testing

In April, when the pandemic hit Sweden the hardest, no provision was in place for widespread testing. On March 30, the Government commissioned the Public Health Agency of Sweden to rapidly produce a national strategy for expanding testing. However, no such strategy was published until April 17. The reason for the delay and what was done on this issue before March 30 remains for the Commission to examine. We will also be investigating and evaluating several other aspects of testing and tracing and the question of whether the testing capacity that existed could have been better used had it been prioritised differently. However, the Commission already considers that even with scarce capacity, all the older people who moved into residential care for the elderly and those who were discharged from hospitals and returned to their residential care home should have been tested without exception.

The ban on visits was imposed too late and was not re-evaluated often enough

The ban on visits to residential care introduced on April 1 was based on sound reasoning purely in terms of preventing the spread of the virus. It was known early on that COVID-19 posed a particularly serious risk to older people. The Commission is not aware of any studies of the actual effects of the Swedish ban on visits to curb the spread of the virus to residential care facilities. International studies have not found evidence for such a ban being particularly effective. Even if the main routes by which the virus entered residential care have not been completely identified, it was reasonable to assume that relatives of the residents could bring the virus with them as it was prevalent in the general population. Therefore, it is the view of the Commission that imposing a national ban on visits was both understandable and defensible. If the ban is assumed to be effective, it also follows that a ban ought to have been imposed earlier, as did in fact happen in several municipalities and with several private principals.

The Government should have allowed the decision to ban visits to apply for a considerably shorter time. A potential extension could then have been considered. The question of the existence of the ban and its limitations of individual rights could then have been more

systematically assessed in relation to the general spread of the virus and the specific regional conditions.

The view of the Commission is further that in the government ordinance imposing the ban on visits, the Government should have made it clear that visits from relatives were to be permitted during the residents' final days of life. The fact that many people died without a relative by their side is unacceptable, even if the ban could be motivated as part of the strategy for limiting the spread of the virus. We intend to return to the question of whether there was legal support for the imposed ban on visits in a later report.

Other shortcomings identified

Guidelines regarding access to hospital care increase risk

Several regions issued guidelines or regulations on priorities. The governing regulations of Region Stockholm issued on March 20 have attracted the most attention. The regulations stated, among other things, that when deciding on hospital care, people in categories 1–4 on the Clinical Frailty Scale (CFS) were to be prioritised. Hardly anyone in residential care for the older people are in the prioritised categories.

The Health and Social Care Inspectorate has shown that there was a marked reduction in the number of referrals to hospitals from residential care facilities for the older people during February–June 2020. However, it is hard to establish whether this type of guidelines led to physicians failing to make individual assessments of care need – as dictated by guidelines issued by both the National Board of Health and Welfare and Region Stockholm. However, it is not possible to rule out the fact that such guidelines – combined with the lack of equipment and partly also staff needed for on-site medical treatment residential care facilities – may have contributed to decisions to administer palliative care instead of hospital care or other active disease-related treatment.

The view of the Commission is that even in a pandemic, guidelines that risk using categories to determine the individual need for care should be avoided. Even though the guidelines state that an individual assessment must always be made, there is a significant risk that this will not be done in a chaotic situation, in which there is a

demand for clear rules of action and a widespread concern that hospital beds and intensive care beds will run out, in combination with online assessments made without sufficient knowledge of the patient. The guidelines must always be drawn up with great care, emphasise individual assessment, avoid simple categorisations and be based on careful ethical considerations.

Lack of physicians present and no individual assessment by a physician

The investigation of patient records for 847 people in 98 residential care units by the Health and Social Care Inspectorate reveals up to about 20 percent of cases were not assessed by a physician at all. In 40 percent of these cases, there was no individual assessment by a nurse either. Furthermore, the investigation shows that not even 10 percent of the patients/recipients of care were assessed at the residential care facility.

It is the view of the Commission that it is unacceptable that there have been cases in which the resident was not individually assessed by a physician and in some cases was not medically examined at all.

Assessment by a physician online is particularly problematic concerning potential hospital admissions. It is likely that the risk of incorrect assessments being made on this issue has been greater during the pandemic, in part due to all the unknown factors surrounding the disease. According to the Commission, it is unacceptable that so many assessments were made online by physicians who lacked previous knowledge of the patient.

Responsibility for the shortcomings

We have found that elderly care was unprepared and ill-equipped when the pandemic struck and that this was founded in structural shortcomings that were known long before the outbreak of the virus. The ultimate responsibility for these shortcomings rests with the Government in power – and with the previous governments that also possessed this information. The Government governs the Realm (Chapter 1, Section 6 of the Instrument of Government) and

should therefore have taken the necessary initiatives to ensure that elderly care was better equipped to deal with a crisis of this nature.