

MC COVID-19

Governmental response to the COVID-19 pandemic in Long-Term Care residences for older people: preparedness, responses and challenges for the future

Sweden

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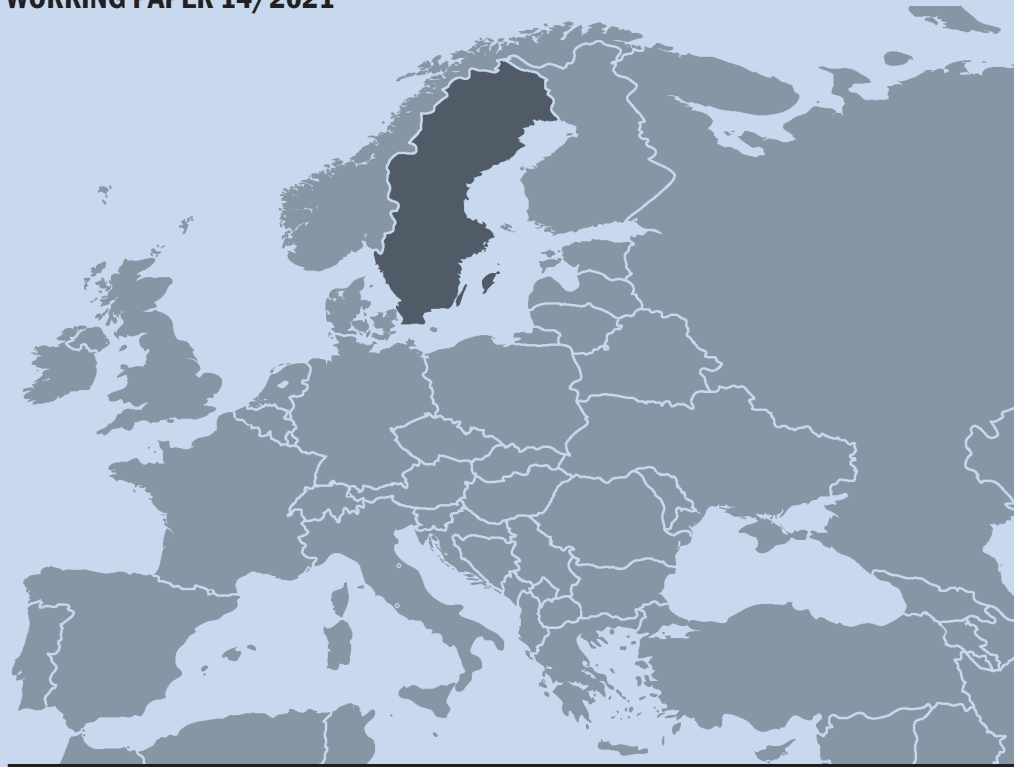
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MC-COVID19

Coordination mechanisms in Coronavirus management between different levels of government and public policy sectors in 15 European countries

The political and administrative management of the healthcare crisis provoked by the COVID 19 is a key issue in preventing the spread of the disease. The Mc-COVID 19 project is set to analyse the socio-sanitary co-ordination procedures in the con-

text of institutionalized older-age care (age group that appears particularly vulnerable in this epidemic context), in Spain as well as in the rest of the EU-15. This study focuses on the articulation of resources between health and social policies, and aim to contribute to improve the effectiveness of the decision-making process and crucial aspects in the fight against the pandemic. Findings also aim to be useful to inform other public policy sectors involved in crisis-related situations.

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1. DESCRIPTION AND ANALYSIS OF THE ROLE OF THE RESIDENTIAL CARE SECTOR FOR THE OLDER-AGE POPULATION IN YOUR COUNTRY (PRE-COVID19)¹

1.1. Trajectory of LTC until the most recent model

Sweden has a well-developed welfare system, providing health care, social services as well as pension and social protection to the citizens over the life course. It has been a public responsibility for centuries to care for older and disabled people. The general principle of LTC policy is to provide publicly subsidised, widely available services (in kind) based on the individual's needs, regardless of economic means and family resources, thereby removing the burden of providing services from the family (Sipilä, 1997). A basic idea behind the universalistic feature of the Swedish welfare system is to make the services affordable for the poor, but still attractive for the wealthier (Szebehely & Trydegård, 2012).

In the beginning of the 1950s, Sweden shifted policy direction in old age care, from “care homes to home care”. This was followed by a rapid expansion of home-based care in the 1960s and 1970s, peaking in the beginning 1980s. Then, during the 1980s, a Governmental commission was working on new strategies to reform the elderly care system in Sweden. In this work, the consequences of the “divided responsibility” for the care of older people whereby health care and social services were provided by two different tiers of local authority - were highlighted. At that time, the county councils were responsible for health and medical care and the municipalities for social services.

The “divided responsibility” caused difficulties in the co-operation between the different parties involved in the care of older people a lack of co-operation which ultimately had repercussions on the elderly. Divided responsibility led to confusion over political responsibility, inefficient utilisation of resources, and problems in everyday care work, etc.

To consolidate financial and care responsibilities it was decided that the responsibility for the care of older people should be borne by one level of local authority: the municipality. In 1992, the Community Care Reform came into force, thereby establishing the structure of LTC that is still in place in Sweden. The 1992 reform - resting on an “ageing in place” policy - implied that the municipalities were given the statutory responsibility for all types of institutional housing and care for older people including the responsibility to provide health care (up to nurse level) to elderly residents, in the institutions. By agreement with the county, the municipalities could also take over the responsibility for basic home health care. However, the responsibility to provide health care does not include medical care that still were provided by primary care doctors. The challenges guaranteeing health care therefore rest extra heavily on the municipalities. Then, it was decided that every municipality should have a Medically Responsible Nurse (MRN). Their area of responsibility became to ensure that the municipality health care is appropriate and safe. The MRN is also a resource in planning of the

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municipally health care, allocating resources and expertise and therefore a key person regarding health care in municipal service and care. To address the historic problem with “bed blockers” in hospital care – patient blocking beds waiting for care to be arranged after the hospital stay - the reform brought forward a new law, giving the municipalities financial responsibility for bed blockers in hospital care (Johansson, 1997).

Then, old age care is based, driven, and financed by the municipalities. Over 160 000 older people are provided service and care in their own home and some 82 000 are provided institutional care in 2019 (NBHW, 2020a). The development that started in 1992 implied a major decentralisation and deinstitutionalisation of old age care, a development further sustained during the 2000s as the municipalities started to downsize the number of institutional beds. This has resulted in a new structure for old age care in Sweden.

The 1990s brought forward another new policy direction, which triggered changes in care of older people: the enhancement of market and private welfare services. This increased reliance on the market was the result of an intense debate regarding the need for improved efficiency of public services. The introduction of market mechanisms or the “privatization of care” has encouraged LTC users’ freedom of choice since the early 1990’s, and this was further reinforced by the introduction of tax subsidy 2007, for purchased help with household chores.

In 2009, a new *Act on Freedom of Choice* gave the municipalities another alternative of contracting providers. The tax subsidies mentioned above further facilitated the introduction of consumer choice models. This model is introduced in about half of Sweden’s municipalities. After needs assessments, the entitled person is free to choose between different (accredited) providers. Competition in this quasi-market is *not* driven by price, as the municipality pays a fixed sum per hour of services to all providers. The new act gives the municipalities another alternative to contract and reimburse alternative providers. Since then, there are several options, first to provide service in-house, secondly to contract out services to private providers or thirdly, to introduce a customer choice model, or use different options for different services at the same time. Relationships between the municipality and service providers – private or public – are governed by means of contracts. In the contracting-out and customer-choice model, the municipality can set quality standards, prices and inspect providers (Meagher & Szebehely, 2013).

In 2010, corresponding legislation was introduced in the Primary Health Care services, giving patients the right to select their primary health care centre. The legislation also meant freedom for providers to establish their services wherever they choose, if they fulfilled certain fiscal and administrative criteria (Burström, et al. 2017). Older people with complex health problems and severe needs, living alone at home, are often dependent on service and care around the clock. A consequence of the marketization of old age care has been a rapid increase in the number of providers of both

in health and social care. Many private providers use (several) subcontractors to be able to provide necessary service. When someone needs help around the clock, this will necessarily result in help by several care personnel, which in turn challenges continuity, security, and patient safety.

1.2. Current arrangements in LTC

Swedish people have a statutory right to claim service and care whenever needed. The provision of LTC is based on a single-entry system; persons in need of help turn to the municipality where they live in order to claim help. Need is determined through a need assessment process, carried out by a municipal care manager. Eligibility to services; home based care as well as institutional care, is not means-tested and there are no national regulations. The municipality decides the service level, eligibility criteria and range of services provided. Individuals can claim services, but they have no automatic right or entitlement to services. If the elderly person requesting services is dissatisfied with the care manager's decision, he or she can appeal the decision in the administrative court.

The current institutional arrangements were laid down in the Community Care Reform when the municipalities were given responsible for all type of institutional care. Then, the responsibility for nursing homes, was transferred to the municipalities, adding to existing residential care facilities, including assisted living and group homes for people with dementia. This shift in responsibility signalled that the nursing homes should not be a part of hospital care according to the Health Care Act, instead a housing option for older people according to the Social Services Act.

Then, the Community Care Reform, with roots back in the 1950s consolidated the ageing in place policy in old age care in Sweden. The reform implied a major decentralisation and deinstitutionalisation of old age care. The new municipal financial responsibility for bed blockers in acute hospital care, immediately led to a rapid discharge of older patients. In turn, this triggered a rapid reduction of hospital beds and during the ensuing almost 30 years hospital bed numbers have declined by more than half. Today the number of hospital beds in relation to the population is one of the lowest among OECD countries (OECD, 2019).

A wave of closures of municipal institutional beds, have since the beginning of the 2000s, resulted in a reduction of nearly 40 per cent of all municipal places (NBHW, 2020b). Coverage ratios, 65 years and older, have correspondingly decreased with almost 50 per cent. The downsizing of municipal institutional care has increased the turnover rate among the residents. National data (NBHW, 2016) show that 10 per cent of those admitted to institutional care deceases within two months, 31 per cent within 12 months and 50 per cent within 24 months. This pattern is confirmed in local studies, showing that the length of stay in institutional care has decreased, with a rapid increase in the proportion of people who moved into institutional care and died shortly afterwards (Schön et al., 2016). Today, the mean length of stay in institutional care is 730 days (SALAR, 2020a).

Ageing in place

The “ageing in place” policy in old age care - moving service and care to people instead of people to service and care, and the option to get necessary service and care in your home instead of moving to an institution - was laid down in the 1950s and has since then been widely embraced by the public.

However, recent decades, the public start to question whether ageing in place has become an alternative forced upon older people and their families rather than an option. That is, research suggests that older people in Sweden are being provided neither with the services and care they need to age in place nor with institutional care. An indication of these problems in Sweden is that a growing number of older people are queuing up at the emergency ward at the hospital (SBU, 2013).

Care of older people is a public responsibility in Sweden, there are no legal obligations or statutory requirements for adult children to provide care or economic security for their older parents. Swedish welfare state programmes are based upon individual independence; family bonds should be voluntary and not obligatory. The underlying philosophy has been to promote maximum independence from the family, even if you need support for your daily living. However, given the public responsibility to cater for older people’s service and care needs, it is still the family and next of kin who are the major providers of help to older people in Sweden (Jegermalm & Jeppsson Grassman, 2012; Ulmanen & Szebehely, 2015; Johansson et al., 2018).

The current development has repercussions on the families, the brunt bearers of care for frail older family members. The decrease of beds in municipal institutional care, combined with the increasing numbers of very old people in the population, means that frail and disabled persons are discharged from hospitals to their own homes, with a need of extensive home help services, and home health care. We are talking about very old people, 85 years and older, whereof a majority is widow women, living on their own.

Many of these older people receive home help, but the issue is whether this is sufficient to provide a safe and good care at home. The day has 24 hours and even with seven or eight visits per day, it is often not enough to provide necessary security for old people. Often the nearby living daughter is the one to fill in the gap. But, as most women in Sweden are working, this adds only more stress to the daily tasks. Studies also show that nowadays, due to the described development, many of all people suffering with dementia is cared for at home (Wimo et al., 2016). This adds further weight to the already arduous situation for many families.

1.3. LTC governance

In Sweden, responsibility for health care and social services is divided between three levels of government. At the national level, parliament and the government set out policy aims and directives by means of legislation and economic incentives. The regions (21 in all) are responsible for the

provision of health and medical care. At the local level, the (290) municipalities are legally obliged to meet the social service, home health care, and institutional care needs of older people.

Regions and municipalities have a very high degree of autonomy vis-à-vis central government. Both have elected assemblies and the right to levy taxes. The regions and municipalities may, within the limits prescribed by existing legislation, decide to what extent they will prioritise older people over other groups. The division of responsibility is reflected in funding responsibilities. Care of older people is almost totally financed by taxes. The user only pays a fraction of the cost (4 - 6 percent). The largest share of the cost (about 90 percent) is covered by local taxes. National taxes cover the remaining part of the cost (about 5 percent). The fact that health and social care services for older people are primarily funded by local taxes confirms the independent role of the local authorities, i.e. their independence of national government.

Access to institutional care is decided in the same way as home help services, i.e. through a process of needs assessment, carried out by the municipal care manager. Eligibility and access criteria may and do vary considerably from one municipality to another. However, the level of dependency and degree of cognitive impairment is often decisive.

Institutions may be run by private entrepreneurs, commissioned by the municipality, which then decide over the placement of the elderly person. In 2019, some 19,2 percent of all older people in institutional care were cared for by private entrepreneurs (NBHW, 2020c). Private institutions, where the resident pays out of pocket does exist, but they are very rare. Regarding facility ownership some 79 percent of the institutions were owned by the public and 21 by private entrepreneurs. Among the privately owned institutions, three per cent were non-profit and 18 percent for-profit (Erlandsson et al., 2013). Recent years, the number of privately own facilities (especially for-profit institutions) have increased, but there is no national statistics showing this development.

The very core of the Community Care reform was the new municipal responsibility for some 31 000 nursing home beds, that prior to the reform were runned by the regions. The responsibility for these more hospital like nursing home beds were “added to” to the different types of residential care facilities already existing in the municipalities. There is no data on how many of these beds and facilities still is in use in its original design. Many facilities have been closed or is been used for other purposes. Others have been rebuilt, modernized, or replaced with alternative housing options.

Today there are altogether some 1700 institutions or units for care of older people in Sweden (SALAR, 2020a). Since the Community Care reform, all types of municipal institutional care have been gathered under one “umbrella” heading; “special housing” with service and care for older people, hereafter care homes. This concept covers nursing homes, residential care facilities such as old age homes, service houses, assisted living, group homes for persons with dementia etc. Since 1992, there are no statistics

collected and available at a national level, of different types of institutional care alternatives for older people.

In October 2019, a total of 81 982 older persons were cared for in municipal institutions (NBHW, 2020a). Coverage ratios, i.e. the number of people 65 years and older in relation to the 65 and older population in institutional care differs widely among the 290 municipalities. The lowest ratio is 0,8 and the highest 8,2 percent and the national average 4 percent coverage (NBHW, 2019).

The institutional concept is wide and includes a variety of care settings where the least common denominator is staffing around the clock. Today three different groups of residents and institutional types of facilities could roughly be identified. It has been estimated that some 35 per cent are nursing homes beds catering for older people with severe somatic illness, 35 per cent dementia beds for people with advanced cognitive decline and 30 per cent residential care beds for people with less severe needs. However, at the same time some two third of the residents are suffering from various degree of cognitive impairment. That means that far from all people with dementia is cared for in specially designed dementia units (Wimo et al., 2016).

1.4. General functioning of the residential care system

The outlook of most municipal long-term care institutions is quite like regular apartment houses, which is also reflected in the housing standard. Three quarter of residents in institutional care have an apartment with 1 or 1½ room, with cooking facilities (kitchenette), a WC and shower (NBHW, 2020c). The residents furnish their apartment themselves to make it as home-like as possible. The resident pays a rent for the apartment, and costs for food and care. According to the aging in place policy, old people living in their apartment and home, should be met as anybody else living in their own and needing help.

Then, “beds” in Swedish long-term institutional care/care homes - are small apartments - usually located along a corridor, often ending in a dining room and a TV room. Many units have balconies attached at each floor. A garden or outdoor space at ground floor is also frequently available. Compared with the old nursing home wards, with multi beds rooms, with bedside tables and medical equipment for oxygen treatment, has today's institutions few similarities whatsoever with old times.

The average age for moving to institutional care is 86 years. Two third of the residents are suffering from various degree of cognitive impairment, which also is the main reasons for admittance to institutional care (Sköldunger et al., 2019). The remaining third of the residents are often suffering from severe medical conditions and functional decline, needing constant support and supervision. Of course, given the fact that there still exist “traditional old age homes” in many municipalities, you could find residents with better health, more physical active and cognitively intact old people.

The main problems in institutional care are in some way or the other linked to the rapid reduction of beds in institutional care. This has created recurrent discussion regarding access to institutional care. Eligibility to institutional care has, according to the public, become absurd in some municipalities, as very high age, living alone, poor medical status, and dependency has not been “enough” to grant a bed in institutional care.

The other ever ongoing debate relates to staffing ratios and the training of care personnel. There are no mandatory staffing levels in the Social Services Act, regulating institutional care. The wording in the Act is that there should “necessary” staffing and that the care should have “good quality”. This is of course interpreted very differently by the municipalities.

Staff ratios, scheduling and rostering are interconnected problems. According to data national average staffing ratios among care personnel in institutional care was 0,3 care personnel per bed, daytime. Comparative staffing ratios for nurses was 0,04 nurse per bed, daytime (NBHW, 2017). In other words, there are no trained nurses on duty all around the clock in the care homes, which of course put a limit for more advanced nursing. The level of training of care personnel has been questioned over the years. And as the residents in institutional care ages, increases frailty, and cognitive impairments, there is a quest more medical training.

Health care is provided by nurses and assistant nurses. Medical care by is provided by the primary health care doctors. The care personnel (mainly assistant nurses and care aids) cater for daily personal care, social activities, and companionship. The care personnel try to engage the residents in baking, cooking and to set the dinner table as well as lighter gymnastics exercises and if possible, to take a walk. The institutions have often an operating manager, often with a social worker training, that cater for to the administrative tasks, economy, scheduling, and rostering of care personnel. The single unit in the institution is usually managed by a nurse daytime. During non-office hours, there are nurses on call as well as doctors if needed.

2. DESCRIPTION OF THE EVOLUTION OF THE PANDEMIC IN SOCIETY AT LARGE, AND IN THE RESIDENTIAL CARE AND HEALTHCARE SECTORS MORE SPECIFICALLY

2.1. General description of epidemic: detection, scope and some data

Timeline

January – The awakening

- 31/1 The first COVID-19 case in Sweden is reported by the Public Health Agency.
- 31/1 The Public Health Agency classifies COVID-19 as an epidemic.

February - Red alert

- 26/2 National Board of Health and Welfare goes up in staff mode (responsibility for Personal Protective Equipment [PPE], planning hospital intensive care, and training of care staff).
- 27/2 The government stated the stocks for PPE are to be good.

Mars - Action taken

- 10/3 The Public Health Agency announces that there is a “very high risk of the spread of infection”.
- 10/3 Many municipalities urge relatives not to visit care homes.
- 11/3 The first death in COVID-19 (Stockholm Region).
- 11/3 The qualifying day in the health insurance is abolished.
- 11/3 The Public Health Agency advises against gatherings of over 500 people.
- 13/3 The government abolished requirement for a medical certificate when on sick leave for the first 14 days.
- 14/3 The government advises against foreign travel.
- 16/3 The Public Health Agency recommends older people to limit contact with others.
- 16/3 The government instructs the National Board of Health and Welfare to ensure the availability of PPE + other healthcare material to regions and municipalities.
- 17/3 The government decides to close high schools, colleges, and universities.
- 19/3 The government decides on a ban on entry from countries outside the EU/EEA.
- 21/3 First death in a care home in the country (Älvkarleby municipality).
- 25/3 National Board of Health and Welfare issues “National principles for priorities in intensive care under extraordinary circumstances”.
- 29/3 The Public Health Agency advises against gatherings over 50 people.

April - The pandemic tsunami

- 1/4 A temporary act on National ban on visits to care homes for older people.
- 1/4 The Public Health Agency issues Regulations and General Advice on everyone’s responsibility to prevent COVID-19 infection. Persons over 70 years of age and those belonging to other risk groups should, in addition to general recommendations, limit their social contacts, avoid using public transport, and avoid shopping in stores, pharmacies or staying in other places where people gather.
- 7/4 The National Board of Health and Welfare issues “Work methods in municipal health and medical care at COVID-19”.

May - Blame and shame

- 7/5 Several political parties demand an independent corona commission.

- 13/5 Continued advise against unnecessary trips abroad.
- 25/5 The state provides extra compensation to the regions for digital care visits.
- 29/5 New demands for a Corona commission from all political parties outside the government.
- 28/5 The Health and Social Care Inspectorate (IVO) publishes the first results of its supervision of elderly care during the pandemic.
- 29/5 The government decides to open high schools, colleges, and universities on June 16.

June - The sequel

- 4/6 The government grants 5.9 billion SEK to the regions for an expanded testing.
- 15/6 Extended ban on visits to care homes until 31 August (finally lifted the 1st of October)
- 1/7 The government appoints a Corona Commission.

The impact of COVID-19

COVID-19 has affected the country in different ways and changed over time. The infection came to Sweden at the end of February and the beginning of March, probably in connection with many Swedes traveling abroad during winter holidays, becoming infected, and spreading the infection when they returned home. During the COVID-19 pandemic, mortality, at the population level, increased significantly in March and April, but followed at a time with slightly lower mortality than in recent years. In June, mortality has approached the average for recent years.

Developments in the spring of 2020 show an excess mortality in the population and increasing with age. As seen in table 2, among those aged 70 and older who died in the spring, almost 29 per cent had home help and 50 percent lived in care homes. Of all older people deceased with COVID-19, place of death was in care homes in half of deaths, 45 percent died in hospital care and some three percent died at home.

If one compare the average number of deaths per 100,000 during week 11 to week 21(not shown in the table), the mortality rate was 46 percent higher in 2020 than in 2016–2019 among those in care homes, 25 percent higher for those older people with home help, and 11 percent higher among those without help. At the weekly level, the increased mortality was greatest at week 15–19. Among people over 70 years of age in care homes, the mortality rate was at most week 16, among people with home help week 19 and among older people without old age care week 17, and then declining. The fact that mortality has fallen during the summer months and onwards, has been interpreted as meaning that those who died in the spring, would have died a few months later in any case.

During the spring, the Health and Social Care Inspectorate (2020) studied the COVID-19 infection in care homes in particular and found that the

Table 1: Deaths per 100 000 inhabitants, Sweden 2015-2020, by month

Month	2015	2016	2017	2018	2019	2020
January	86,0	85,4	89,9	84,2	79,2	78,1
February	88,9	82,0	85,9	88,2	78,3	75,5
March	85,9	80,1	79,7	90,1	73,6	80,1
April	79,2	76,4	77,1	76,9	71,9	102,0
May	72,8	69,8	72,2	66,3	67,4	83,4
June	70,0	67,7	68,1	65,6	64,6	71,7
July	70,4	70,6	66,7	71,1	65,4	66,0
August	67,3	69,8	67,3	66,3	66,1	64,2
September	53,8	42,2	43,8	49,7	40,4	44,3

Source: Statistic Sweden, 2020

mortality rate in COVID-19 in Swedish care homes is spread across the country, but is mainly concentrated to 40 municipalities where almost 70 percent of mortality has occurred. Of the 40 severely affected municipalities, initially only 60 percent judged to have necessary conditions for individual assessment and treatment linked to COVID-19 in care homes. In the other 250 municipalities, 67 percent stated that they had correspondingly necessary conditions.

A study of patients admitted to Karolinska Hospital in Stockholm showed that 3 out of 4 patients with COVID-19 who were cared for at the hospital in the spring of 2020 survived (Religa & Hägg, 2020). The risk of dying or not being discharged to the home was mainly linked to frailty, measured with the Clinical Frailty Scale. Chronological age and comorbidity were also associated with increased risk, but to a much lower degree than fragility.

COVID-19 first affected the Stockholm region, followed by Uppsala and Sörmland. Later in the process, the infection was transmitted to southern Sweden and the Västra Götaland region. It is interesting that in the Skåne region the infection has been significantly lower than in Stockholm. One explanation may be that the infection spread later in Skåne and that the introduced infection restrictions had an infection-limiting effect. The Stockholm region has been hit the hardest when it comes to adopting the infected and the dead. This also applies to the number and proportion of deaths in care homes. Approximately 7 percent of all elderly people who lived in care homes died during the spring with covid-19, which is relatively 2-3 times more than in other regions in Sweden.

Among those who died in the spring, over 70 percent were 70 years and older, while differences between the sexes were very small. In some districts in the city of Stockholm and in Gothenburg, with a large proportion of the population

Table 2: Deaths in COVID-19, among 70+ years, by age, gender type of care and place of death, as by September 21st, 2020

Age	Total		Men		Woman	
	Number	%	Number	%	Number	%
70-74	479	9,2	330	12,3	149	5,9
75-79	729	14,0	445	16,6	284	11,3
80-84	1 109	21,4	643	24,0	466	18,5
85-89	1 344	25,9	652	24,3	692	27,5
85+	2 878	55,4	1 263	47,1	1 615	64,2
90+	1 534	29,5	611	22,8	923	36,7
Type of old age care	Number	%	Number	%	Number	%
Care home	2 631	50,6	1 131	42,2	1 500	59,7
Home help	1 477	28,4	795	29,7	682	27,1
Place of death	Number	%	Number	%	Number	%
Hospital	2 318	44,6	1392	51,9	926	36,8
Care home	2 576	49,6	1 121	41,8	1 455	57,9
At home	178	3,4	95	3,5	83	3,3
Numbers of death	5 195		2 681		2 514	

Source: National Board of Health and Welfare, 2020 d.

with a foreign background, there was an overrepresentation of infected and deceased people. Many of them have come rather recently to Sweden, have little education, and may not even understand Swedish. They frequently live two or more generations together or in otherwise cramped households, increasing the risk for contagion. An analysis of raised mortality risks spring 2020 concluded that there was a host of factors accumulating to raise mortality for these groups, both cultural and social (Hanson, et al., 2020).

An added risk was the fact that many women from these areas work as nurse assistants or care aids in care homes and frequently commute by public transport to their job, suggesting a vicious feed-back between care homes and other public services and the local environment. An additional risk factor is the fact that many care homes – also common in the home help service - hire temporary or “substitute” staff to keep down costs, workers who often cannot afford to stay home if they feel sick – they are not covered by the Swedish health insurance - and then may infect older persons and colleagues (Hanson, et al., 2020).

Table 3: Deaths in COVID-19, among 70+ years, by region and type of care, as by September 21st 2020

Region	Total		Care home		Home help	
	Number	%*	Number	%**	Number	%**
Sweden	5 195		2 631	50,6	1477	28,4
Stockholm	2 044	39,3	1 047	51,2	564	27,6
Västra Götaland	797	15,3	463	58,1	182	22,8
Skåne	241	4,6	96	39,8	91	37,8
Östergötland	241	4,6	139	57,7	48	19,9
Södermanland	226	4,4	89	39,4	68	30,1
Uppsala	218	4,2	107	49,1	67	30,7
Dalarna	203	3,9	88	43,3	67	33,0
Västmanland	170	3,3	117	68,8	19	11,2
Jönköping	168	3,2	83	49,4	50	29,8
Gävleborg	159	3,1	72	45,3	57	35,8
Örebro	143	2,8	52	36,4	63	44,1
Västernorrland	115	2,2	60	52,2	32	27,8
Kronoberg	87	1,7	45	51,7	32	36,8
Norrbottn	80	1,5	41	51,3	27	33,8
Halland	72	1,4	44	61,1	18	25,0
Värmland	65	1,3	16	24,6	31	47,7
Kalmar	64	1,2	19	29,7	31	48,4
Jämtland	59	1,1	36	61,0	14	23,7
Västerbotten	25	0,5	9	36,0	10	40,0
Blekinge	X		X		X	
Gotland	X		X			

Note: *Percentage death per region related to total deaths. **Percentage death, by age and related total. X=Data protected for secrecy reasons deaths in the region. Source: National Board of Health and Welfare. Death causes

The extent to which the cause of death was COVID-19 is difficult to determine. In a study of deaths sometimes among older people who died at home or in care homes in Östergötland, it was found that only a small proportion of the deaths were caused by COVID-19 (Pramsten, 2020). COVID-19 was estimated to be the direct cause of death in 15 percent of deaths. For most of the deceased - as many as 70 percent - COVID-19 was a contributing factor rather than a direct cause. In 15 percent, the cause of death was judged to be other diseases, then most often heart disease. This means that even if the deceased was (found) infected with COVID-19, it is not a given that this was the (main) reason why the person died.

2.2. The effects of the epidemic on the healthcare system

The COVID-19 epidemic has had enormous consequences for the Swedish healthcare. Even before the epidemic, hospital care was characterized by long waiting times, queues for operations, congested emergency rooms and wards. The lack of nurses, especially specialist nurses, meant that even though there were beds available in the hospitals, they could not be kept open due to staff shortages. The Swedish strategy for dealing with the pandemic has therefore to a large extent been focused on trying to prevent intensive care from collapsing. The regions therefore began to rapidly expand hospital bed capacity for intensive care, partly by opening new beds or freeing up beds within the hospitals for COVID-19 care. To open new hospital beds, the regions started recruitment campaigns to attract retired staff, staff who had left the health service for other work, and students to take work in the hospitals or to fill the gaps after other care personnel, re-located to intensive care.

In the Stockholm region and in Gothenburg, additional care resources were created by building two field hospitals, to relieve the hospitals in the region. Resources for intensive care, including respirators and staff to be able to staff the expanding intensive care, were given the highest priority, as well as access to necessary protective equipment and medicines. Equipment, organization and routines for testing and analysis also needed to be developed.

The situation in primary care before the pandemic was often characterized by long waiting times for visits to doctors, understaffing of doctors in many parts of the country or dependence on “relay doctors”. To minimise the risk of getting COVID-19 and to cope with an increased demand for health care, treatments or visits to the region’s primary health care centres were cancelled, either by the patient itself or by the health centre.

Since primary care doctors are also responsible for the medical interventions in municipal care homes their participation in care came under great pressure. The National Board of Health and Welfare recommended that physical doctor visits to care homes should be minimized due to the risk of infection and that doctor consultations should be conducted remotely, over phone or video (NBHW; 2020d). In several regions, recommendations were issued that people in care homes who fell ill with suspected or confirmed COVID-19, should primarily be cared for in the care home and not referred to hospital. There are examples of cases where morphine and anti-anxiety drugs have been prescribed for palliative purposes, when other older people have been treated with drip and oxygen and become healthy. That palliative care was advocated, some believed, was due to a lack of support from primary care physicians. In Region Stockholm, physical doctor visits in care homes decreased by 24 percent the period January to July compared to the same period in 2019. During the pandemic, every third doctor’s visit in care homes has been conducted remotely (DN, 2020). In July, the Health and Social Care Inspectorate (IVO) presented results from their ongoing large-scale inspection of 1,700 care homes. IVO stated that many care

homes did not have enough contact with doctors, the assessments of older people's care needs were in several regions general rather than individual at the beginning of the pandemic, and that palliative care sometimes were initiated on a routine basis instead of admitting to hospital care. In every fifth region, palliative care was provided too quickly (Health and Social Care Inspectorate, 2020).

The municipalities are responsible for home help and home health care, which is part of the municipal LTC. However, in the Stockholm region, responsibility to provide home health care rests on primary health care. Home health care is responsible for medical care, but its patients are to a large extent also in need of help from the municipality's home help service. Nearly 70 percent of all elderly people with home health care also have help from home help (NBHW, 2019), i.e. many older people in this situation are very dependent on daily help, supervision, and care. Even before the pandemic struck, municipal LTC and home health care were under severe pressure, with large staff turnover, a shortage of trained staff and poor working conditions (Strandell, 2019).

2.3. The epidemic in the public and political debate

The media coverage of the epidemic gained historical proportions in the spring of 2020. In newspapers, radio and television, the epidemic, its development, and consequences, especially in terms of the number of infected persons and deaths, dominated the reporting. Social media has been filled with various theories about how the infection spreads, and how to protect yourself and self-care of COVID-19. The centre of this gigantic news feed came since mid-March to become the daily press conferences, where responsible authorities; The Swedish Public Health Agency, the National Board of Health and Welfare and the Swedish Agency for Civil Protection and Emergency Planning reported on the development of the pandemic.

Corresponding press conferences have also been held in the country's regions and in some cases in the municipalities. There has also been continuous information about the "Corona situation" on the websites of authorities, regions, and municipalities. Some municipalities have refused to disclose information to regional media about infections or deaths in LTC, with reference to patient confidentiality. However, with the support of the principle of openness and the threat of legal sanction, the media have gained access to the information, albeit with some delay.

Continuous statistics on the development have been published on the authorities' websites, such as the number of infections, deaths and the number tested for COVID-19.

Similarly, several major newspapers have commissioned opinion polls which, among other things, showed the extent to which the population has followed the authorities' recommendations and the confidence they have had in the authorities' way of dealing with the infection, as well as in the government and political parties. National media have also initiated

processing and compilation of the statistics, and elaborated investigative journalism, focusing on the excessive deaths in care homes and the reasons for this. Regional and local media have often followed up on corresponding developments.

The focus of the general debate and main concern has shifted during the spring and has been affected by how the epidemic has developed over time. It is about everything from the government's actions to the political opposition's comments on the development. The debate focused on the actions of responsible authorities, with contributions from pensioners' organizations, healthcare professions, care workers unions and the public. The newspapers' contributor pages and social media have been filled with posts and comments on the Swedish strategy to combat the epidemic.

Sweden's strategy meant that intensive care would be protected from collapsing. It was above all a matter of having sufficient resources for those affected by COVID-19 and who would need intensive care. On that basis, the recommendations to the public, on hand hygiene, staying at home in the event of symptoms of illness and social distancing were formulated as a way of limiting the spread of infection. In addition, there were later bans on larger crowds, travel restrictions and the closure of high schools and universities.

A central part of the Swedish strategy is about "protecting the elderly". In the Swedish Public Health Agency's recommendations, people aged 70 and older (and younger people with underlying diseases) are singled out as a special risk group for being infected. In addition to the general recommendations on hand hygiene and social distancing, they urge the risk group to limit their social contacts, to avoid using public transport, and to avoid shopping in stores such as pharmacies and grocery stores or other places where people gather. And above all, not to have direct contact with other people, including family and children and grandchildren. If you want to meet your family, it must be done outdoors, at a proper distance.

When first local and then a national ban on visiting all institutions for the elderly was introduced, this further affected the elderly. Opportunities to visit one's spouse or partner or parent were stopped, a restraining order that applied until 15th October 2020.

In parallel with these discussions, of course, concerns about the economy for individuals, companies and the country have dominated during the spring. Many companies, large and not least small, risk going bankrupt. Even if there is a system of labour market insurance, this is not enough for everything when practically an entire country was at a standstill. The government has in turn initiated large financial support packages in several areas of society to reduce the long-term harmful effects. Since the economy is highly dependent on the outside world, the pandemic's will be a global development, something that obviously affects the development in Sweden.

The COVID-19 epidemic has entailed a gradually growing "care debt", i.e. many planned operations and treatments that have been suspended due

to the spread of infection in society. SALAR reported in early August that about 180 000 operations have been cancelled or postponed due to the pandemic. For the healthcare system, it means an enormous commitment to start working on the queues in healthcare, something that will also require extra resources. How this work is to be organized and financed is an ongoing and growing problem.

A related problem that has recently been highlighted in the debate is the long-term effects on public health. Nobody knows today what effects the pandemic will have in this regard and what could be done to reduce the negative effects. The Public Health Agency (2020) conclude in a report in October that continued social restrictions, especially for the elderly, the negative effects of the epidemic on public health can be extensive. Analyses also show that the current recommendations have resulted in a decline in mental health among certain groups and may even have an adverse effect on physical health. These negative consequences are likely to worsen the longer the recommendations remain in place. There may also be a considerable backlog of healthcare needs among this group.

Ageism

In May and June, the general debate has come to be about the results of the Swedish COVID-19 strategy in general and especially about the “failure” to protect the elderly. The focus of the discussion has been on what regions and municipalities have done or should have done for others to prevent the infection from “getting in” to people who have help at home or live in care homes.

At first, the authorities claimed that it was visitors to the elderly (before the restraining order) who brought the infection, but pretty soon it was understood that it was the staff who brought the infection to and between the elderly. It can of course be staff with asymptomatic COVID-19, but it was not discovered, as the staff was not regularly tested for COVID-19. This is a form of indirect ageism, as the care staff felt that they were blamed for the infection entering care homes, while the staff at the hospitals were hailed as heroes in the media. However, the developments, revealed major shortcomings in working conditions, organization and skills in elderly care. Something that has been the subject of a great discussion has been access to protective equipment and knowledge of how to protect yourself and the person you are helping from becoming infected.

In May, a discussion also started about whether older people were not given priority for hospital care but were left behind for the younger ones. The statistics showed that those who were subjected to intensive care were younger, while the majority of those who died were older. Some argued that older people were not given priority, even though there was bed capacity for care in hospitals (as well as in geriatrics). Individual doctors believed that this was the case and that the National Board of Health and Welfare’s prioritization guidelines were not always followed, due to the chaotic situation in many hospitals. Others argued that the explanation was

that primary care followed the general recommendations (NBHW, 2020e) not to refer older people to hospitals, but that those with symptoms should be cared for at home or in their care home. The care that older people received at the care home has in turn been criticized for being passive and all too often dealt with palliative care instead of treatment. When the primary care physician did not know the patient or when the contact took place over the telephone and palliative care was prescribed, there was, according to many commentators, an obvious risk of mistreatment and example of ageism. These issues are currently investigated and scrutinized by the Health and Social Care Inspectorate and will be reported to the Corona Commission.

The political discussion

In February, the political discussion on COVID-19 was virtually non-existent. In March, the situation was characterized by a general support of all political parties behind the Swedish authorities' and the government's handling of the pandemic. There was a "political peace". In April, the tone of the political debate changed when the death toll among older people in care homes rose rapidly. The big question was how the infection could have entered the home help service and the care homes and if it had been possible to prevent this? When the pandemic swept through in elderly care in the spring of 2020, the inability of the government and the responsible authorities to anticipate this development was questioned. Deficiencies and problems in elderly care were known to their former and often pointed out. "Every person with insight into elderly care could understand how it would go" (Professor Ingmar Skoog, April 16, 2020). When the government and the authorities, in response to rising death rates in nursing homes, did not know or could not explain this, it appeared to be either clueless or irresponsible. Knowledge about the vulnerability of elderly care existed previously but was not used.

A debate started about what was behind the development and where the staff's working conditions in the nursing homes came into focus. Lack of protective equipment, basic hygiene routines and weak work management were pointed out as explanations. An important explanation was that 30–40 percent of all employees were hourly employees, which means that they did not receive any sickness benefit when and if they stayed at home due to illness, which contributed to the spread of infection.

At the end of April, Minister of Social Affairs Lena Hallengren stated in an interview that "We have failed to protect the elderly" and in May there was a consensus that the government and the authorities had failed to protect the elderly from COVID-19. Demands were made to greatly expand the test activities throughout the country and that those who worked in elderly care should also be tested. The government called on the regions to rapidly expand testing activities, promising that the state would bear all the costs of testing activities, but the response was weak. Only in June - July did the test activities start on a large scale, when even people with symptoms could be tested.

In May, the political opposition on several occasions demanded that the government immediately should appoint a Corona Commission, which would evaluate the Swedish COVID-19 strategy and its consequences. After some time of hesitation and pressure, the government decided on this on July 1, 2020. A first interim report with special focus on LTC services for older people, particularly regarding the high number of deaths in care homes, will be presented on November 30, 2020. A second report is expected on October 31, 2021, and a final report on February 28, 2022.

However, after the summer, in September and October, the pandemic and its consequences have lost its political explosiveness. The Swedish COVID-19 strategy is not questioned by the political parties in opposition, but instead crime, national defence and immigration issues have now regained their position on the political agenda.

3. DESCRIPTION AND ANALYSIS OF THE MEASURES ADOPTED TO ADDRESS THE IMPACT OF THE PANDEMIC ON THE RESIDENTIAL CARE SECTOR FOR THE OLDER-AGE POPULATION IN YOUR COUNTRY

3.1. Background of preparedness for the Crisis

Sweden's crisis preparedness changed radically in the early 2000s. Previously, there were large emergency stocks of food, medical equipment, and medical supplies. The emergency stocks and the organization's ability to respond rapidly to crisis, e.g. epidemics, were reduced in the late 1990s. Regarding medicines, the state-owned Apoteksbolaget was responsible from 1970 for keeping stocks of medicines and medical supplies. Since 2002, there are no national guidelines for stocks of healthcare equipment or medicines, as it is up to each region to be responsible for this, i.e. crises preparedness is decentralized.

In 2006, a new law on crisis preparedness was introduced, *Act on municipalities' and regions' measures before and in the event of extraordinary events in peacetime and heightened preparedness (2006: 544)*. The law prescribes that municipalities and regions must take measures before and in the event of extraordinary events, such as forest fires, heatwaves and pandemics, that may lead to serious disturbances in society. According to the law, risks, and vulnerabilities in one's own operations, such as home help services and care homes, must be analysed and prevented in contingency plans. Vulnerability analyses and contingency plans are a prerequisite for being able to coordinate and collaborate between government agencies, regions, municipalities organizations, and companies in crisis situations. However, the law does not provide precise instructions on what the vulnerability analyses and contingency plans should look like. The Agency for Civil Protection and Emergency has issued instructions to support regions and municipalities on how to work out local plans.

In Sweden, there is no national coordination regarding the purchase of protective equipment, but it is up to each of the 21 regions to handle this. One

explanation for the lack of access to protective equipment was that many regions do not have large stocks at all, but usually acquire equipment “just-in-time” in line with consumption in healthcare. When infected patients then came under hospital care, the consumption of protective equipment increased more than a hundredfold in some places. When the regions and municipalities tried to buy new protective equipment, they were forced to compete with national purchasing players from other countries, which made it difficult to get opportunities to buy protective equipment at all.

The Agency for Civil Protection and Emergency Planning has the national responsibility, while the County Administrative Board has the coordinating responsibility for emergency preparedness for the municipalities in each county. A central part of the contingency plans is the extent to which they can be helpful when preparing a society for a pandemic. For example, a municipality, region and company must be able to show how much damage a pandemic risk causing to people, property and businesses, how effective various countermeasures could be, how many aids must be available to be prepared for a pandemic.

As there is no national compilation or transparency in the municipal contingency plans, it is not possible to say whether the municipal contingency plans contain any analyses of the vulnerability of the elderly care activities or not. However, during the spring, it was evident that relevant vulnerability analyses were lacking, and contingency plans were often elementary and standardized. In a review carried out in February 2020, i.e. before the pandemic started, it was found that (only) 43 percent of the municipalities had updated contingency plans (NBHW, 2020f). This turned out to be a tough reality at the beginning of the pandemic when it was shown that the regions and municipalities lacked sufficient stocks of protective equipment such as face masks, visors, and protective coats for care. This also applied to equipment such as respirators, which was a major shortcoming during the initial weeks of the epidemic.

3.2. Impact of the Epidemic on Care Homes and Policy Responses

The pandemic hit older people and old age care very hard. During April, the situation became almost chaotic in some municipalities, with continuous reports of increased cases of infection and deceased people, especially in care homes.

How the infection “slipped in” and passed on in the care homes has been intensively discussed. In some cases, these were elderly patients who was discharged from hospitals that were infected. Visiting relatives may also have brought the infection with them, which led to local ban on visits to care homes in many municipalities as early as March. Other visitors, such as deliveries of goods and craftsmen, may also have spread the infection. The extent to which it was the staff who brought the infection to the care homes cannot be demonstrated. Given the COVID-19 social spread, it is likely that staff with asymptomatic infection have introduced the infection without even knowing that they were carrying the infection. The discussion about the role

of staff in the spread of infection has been focused on the fact that about a third of the staff were paid by the hour and therefore may not have stayed home due to illness, because they were not paid when not working.

Once the infection has entered a care home, the lack of protective equipment has been pointed out as an additional reason for the spread of infection. Many municipalities did not have any major stocks with protective equipment. There was a lack of everything from alcohol disinfection to gloves, protective coats, and face masks. Protective visors were usually not available at all. In many care homes, but also in the home help services, it was unclear if and when personal protective equipment would be used, i.e. if you would always have gloves, a face mask and a protective visor in the daily care work. It has also been pointed out that there have previously been shortcomings in basic hygiene routines (NBHW, 2020b) and that the staff do not have sufficient competence to protect themselves and the elderly from infection.

When staff were also infected, it put increased pressure on the municipalities to recruit staff to replace the sick. Staff shortages arose both in the home help service and in care homes. This meant that the temporarily employed staff had to move “between” both the home help services and the care homes, which increases the risk of passing on the infection. The staff employed in this situation seldom had adequate training and often a lack of competence in basic hygiene routines. In some municipalities, for example in Stockholm, flight attendants, restaurant staff and other occupational groups who became unemployed due to the pandemic, were quickly retrained as care aids to help relieve the load on the overburdened staff in municipal LTC and the healthcare. An additional contributing factor to the spread of infection in the institutions is that the residents infected each other. As two thirds of all residents are cognitively impaired, it is difficult to prevent contact with other residents and those who have been infected.

When the infection struck the care homes, access to protective equipment became an acute problem. Help from the regions were scarce and the usual ways to purchase material did not work. In many municipalities, local stores, companies, and voluntary organizations mobilized their help with e.g. making hand sanitizer, protective coats and even visors.

Next, it was a problem whether the staff having knowledge of basic hygiene routines and applied in daily work. Therefore, in many care homes, various initiatives were taken to manage the risk of infection. Cohort care, COVID-19 team, online rapid training in hygiene knowledge, enhanced hygiene routines are some examples. The City of Stockholm as well as other municipalities have also used short-term places for the care of, for example, people who have previously been hospitalized and infected with COVID-19. In many care homes new cleaning routines were introduced. In some care homes where opportunities existed, cohort care was introduced, which means trying to separate infected from non-infected people among the residents. In the home help services, in some larger municipalities, so-called COVID-19 team were organized, i.e. a group of staff who are responsible for all care for people with suspected and or established infection who live at home. In

some care homes, COVID-19 teams have been combined with cohort care, i.e. special staff care for infected separately from others (SALAR, 2020b).

Some municipalities have also paused admittances to care home, to prevent further spread of infection. On the other hand, families have alerted about neglect in care homes, about poor information and not being given the opportunity to say goodbye when a relative is dying at the care home. Pensioners' organizations have complained about the lack of medical expertise in care homes and the lack of geriatricians in municipal old age care. Also, home help services have been affected. In a review of new applicants for home help during the spring 2020 in Sweden, 45 percent fewer persons applied for help, compared to the years 2015 -2019 (NBHW, 2020g).

The epidemic and its consequences have not implied any changes in responsibilities with regard to the institutional care of the elderly, with the exception of the national ban on visits to homes for the elderly, which was introduced on 1 April. During the pandemic, there have been no changes in the relationship between service and care operated by the municipality or private companies.

Sweden's municipalities and regions (SALAR) have defended a more restrictive use of protective equipment, something that the union Kommunal has protested, and taken to judicial review. SALAR has also defended the prioritization of emergency care, as well as the fact that the state did not pursue the test activities during the spring. SALAR have also placed great demands on the government to have the care costs and the costs for the "care debt" covered by extra funds from the state. Further, SALAR made a request to the government at the end of April to receive legal support to be able to isolate infected people from non-infected residents. The government rejected this request on the grounds that it was a constitutionally protected right. The National Board of Health and Welfare has pointed to shortcomings in the coordination between regions and municipalities. Some municipalities state that they have received poor support from the region's infection control doctors and from the doctors who are responsible for medical supervision and support for residents in care homes. The overall assessment is that many efforts were made far too late. That the municipality and the care homes were given lower priority over healthcare when it comes to testing and infection tracing.

There has been a growing discussion about the long-term consequences of the pandemic, both in the general population and among the elderly. As early as the beginning of March, many municipalities introduced recommendations not to visit relatives in care homes. The national ban on visits to care homes, which has been extended in stages, has received increased criticism. The staff at many nursing homes have taken various initiatives to break the isolation in the care home. The staff has tried to help the elderly to digital contact with families. Plastic screens or walls, both indoors and outdoors, have been set up to make it possible to meet in safe forms. The opportunities have also been used for the elderly to meet their relatives outdoors, whenever possible. Various creative outdoor activities, such as

choir singing in the garden, have been appreciated by residents and staff. However, it is a tragic fact that many care home residents died without being attended by families and close relatives due to the pandemic.

At the time when the specific recommendations for those 70+ was lifted, the 22nd of October, the Public Health Agency (2020) published a report based on data from international research, Swedish surveys, meetings with pensioners' organisations and organisations representing the interests of foreign-born citizens, as well as data from the healthcare national helpline 1177. The report stated that the recommendations have resulted in a decline in mental health among certain groups and may even have an adverse effect on physical health. These negative consequences are likely to worsen the longer the recommendations remain in place. There may also be a considerable backlog of healthcare needs among this group. This report was a strong motive to abandon the special recommendations for those 70 years and older.

The criticism has been directed at both the Swedish Public Health Agency and the Swedish COVID-19 strategy in general, the ban on visits to care homes, the late test activities, and the question of whether or not to recommend face masks. The state and the regions have been criticized for the shortcomings in preparedness and warehousing of protective equipment, together with shortcomings in management, organization, and cooperation.

3.3. Interviews – National Board of Health and Welfare and cases of 2 specific care homes

The interviews were carried out in early September 2020, via telephone and Skype. At the time when the interviews were conducted, the infection situation had improved compared to the spring.

For this study we interviewed:

- the senior public health advisor at the National Board of Health and Welfare,
- a manager for a care home in Stockholm,
- and a manager for a care home in a rural municipality in the middle of Sweden.

The interviews aim to shed light on the decentralized structure of the Swedish LTC system by one interview with a top-down perspective and two providing a bottom-up perspective.

Interview 1: The National Board of Health and Welfare

The first interview was conducted with the senior public health advisor at the National Board of Health and Welfare (NBHW), hereinafter referred to as interview person 1 (IP1). NBWH is a government agency under the Ministry of Health and Social Affairs, with a wide range of responsibilities and duties within the fields of social services, health and medical services, patient

safety and epidemiology. Amongst other things, NBHW issuing provisions, regulations, guidelines and general advice, evaluating legislation and activities conducted by regions and municipalities. Other important responsibilities are to develop and produce the official national statistics within the health and social care services sectors.

NBHW is an important stakeholder in providing support to regions (health-care) and municipalities (eldercare) during the COVID-19 pandemic. IP1 describes that NBHW has gradually been assigned new tasks and roles that are handled by a special group that should support the regions and municipalities in their work with COVID-19. NBHW support and coordinate the crisis preparedness in the 21 regions, and also collaborate with the regional preparedness organisations, other competent authorities and the Swedish Association of Local Authorities and Regions (SALAR).

Situation reports

In collaboration with the Swedish Civil Contingencies Agency (MSB) and the County Administrative Boards, NBHW collect information and make assessments of regional and municipal needs of personal protective equipment (PPE) and medical supplies. Based on the information from the regions and municipalities NBHW conduct different kinds of analyses that are turned into situation reports. These reports of the situation are for internal use at the NBHW for daily management of the COVID-19 response, but also for a more long-term perspective use or are aimed at other stakeholders. NBHW deliver situation reports regularly to the Government and Government Offices and to the MSB.

Coordinate and provide resources

Based on the needs of support reported by the County Administrative Boards and the regions, NBHW coordinates and provides resources and support from other stakeholders and government agencies, for example the Swedish Armed Forces and MSB.

Assist with coordinated purchases of medical supplies

The 21 regions and 290 municipalities are responsible for everyday purchasing, delivery and receipt of PPE and medical supplies. During the COVID-19 response, NBHW has been commissioned by the Government to assist coordinated purchasing from the national level and to secure access to PPE and other supplies if the regional or municipal capacity for this is insufficient. NBHW is also commissioned to assist with redistribution of equipment and supplies, if needed. NBHW represent Sweden in the EU joint procurement of personal protective equipment.

Distribution of new medical supplies and redistribution of medical supplies

A further commission from the Government authorises the NBHW to decide on the use of resources in regions and municipalities when it comes to

supplies in the healthcare system. This allows NBHW to redistribute existing medical supplies and to distribute new medical supplies between regions and municipalities. This is done in collaboration with MSB, the Swedish Armed Forces and the Swedish Red Cross.

Domestic production of medical supplies and PPE

NBHW regularly contracts Swedish companies to increase production of medical supplies and PPE. There is an ongoing discussion with other stakeholders to purchase and increase production of supplies. NBHW investigates how to find new ways to manufacture PPE and provide medical supplies to the Swedish market.

Coordination of intensive care unit (ICU) beds

NBHW has been commissioned to coordinate ICU beds. The coordination is based on the daily situation reports, both with regards to available and occupied ICU beds on national and regional level. NBHW has supported the regions in increasing the number of ICU beds, for example, by adding resources such as medical devices and field hospitals and a coordinated collaboration with the Swedish Armed Forces.

Prognoses and planning for different scenarios

NBHW collaborates with the Public Health Agency of Sweden (FHM) to produce prognoses for ICU occupancy. They also support some regions to assess the need for post-ICU care. Another task is to investigate other possible scenarios that could occur while the COVID-19 pandemic is still ongoing, and how these scenarios might affect the healthcare system.

According to IP1, their team became aware of the seriousness of the COVID-19 pandemic at an early stage and realized that it would affect the LTC for older people. IP1 started to work actively on COVID-19 related issues at the beginning of March. Early efforts included to produce COVID-19 status reports, establish contacts with other authorities and organisations such as SALAR, the Swedish Nurse Association (section for Medically Responsible Nurses), the Health and Social Care Inspectorate (IVO), the Swedish Work Environment Authority (AMV) and the FHM. IP1 highlighted that the exchange with the nurse association has been valuable in the development of various knowledge support. NBHW has also had numerous meetings with SALAR and heads of the municipal social welfare. The overall collaboration has been useful, according to IP1.

NBHW highlighted the responsibilities according to laws and regulations to raise awareness among municipalities at an early stage in the pandemic. The responsibility to practice hygiene routines and follow up the compliance among staff was communicated. The risk of shortage of staff due to sick leave was put to attention. The NBHW has provided support with, for example, a broad range of timely information to staff and management teams in municipalities and regions, web education on hygiene routines and a web

education for introduction of new staff members. Issues concerning PPE was high on the agenda. NBHW had contacts with AMV and FHM. The supply of PPE was a complex matter, due to the involved authorities' different responsibilities and because of shortages of equipment. FHM are experts on the disease and responsible for risk assessments, while AMV are responsible for the regulations to protect the staff, and NBHW are responsible for regulations on basic hygiene routines to protect patients. In addition, NBHW were given the complementary function to help with the supply of PPE. IP1 stressed that there has been a need for a close collaboration on issues regarding PPE. On top of that, there was an uncertainty about what level of, and what situations, protection was required. As the world market on PPE collapsed, this became a huge issue. Given the lack of knowledge about the disease and many uncertainties, IP1 thinks that the collaboration between the involved authorities and organisations worked relatively well.

In April, both the Minister for Health and Social Affairs, Lena Hallengren and the state epidemiologist at FHM, Anders Tegnell stated that Sweden has failed to protect older people, particularly those living in care homes.

As described in the background, there have been cutbacks in municipal institutional care in the last few decades when more people instead are offered social and medical services in their regular homes. These cutbacks of care homes have raised the needs threshold so that only the most frail and dependent older people are eligible for and can access a care home.

IP1 argue that there is a need to strengthen the resources in terms of medical competence in care homes and home care according to the changed health care needs and improved options to give health care in regular homes and care homes. An action plan to strengthen health care in municipalities was developed by NBHW in 2018 and NBHW has been given an assignment to implement the action plan. NBHW has also published a strategic plan to support the transformation of the health care system toward a more patient oriented health care system and one objective is to improve collaboration between health care and social services provided by municipalities and health care provided by regions. The collaboration with regions is crucial because of the obligations for regions to provide medical doctors to serve patients in care homes and with home care.

It seems that the infectious disease risk at the community level is of great importance for the COVID-19 situation in care homes. It was a quite extensive spread of infection in the municipalities where many persons were infected in care homes. There are, however, a relatively small number of municipalities that have had a severe spread of infection during springtime. If you look at Stockholm, the infection has not entered all care homes, but certain care homes have had many residents infected, and there is probably a combination of explanations for the situation. Compliance to basic hygiene routines, actions by management teams, staffing and organization of work in care homes matters. /.../

It is not easy to sort out accountability for each actor [i.e. for stopping the spread of infection] in the Swedish model. But there is an overarching legal responsibility for regions and municipalities as principals for health care, for e.g. to provide conditions for good quality health care services. The Health and Social Care Inspectorate conducts supervision and issues permits to care givers. The nurses, assistant nurses and the care aids at the care homes have often made a great effort during the pandemic according to the conditions given. I would not say that they have failed, but they have certainly been faced with difficult tasks, and in some cases it, unfortunately, has resulted in a tragic outcome. But one should not forget that there are many people who have worked very hard and made good efforts and done everything to stop the spread of COVID-19 in care homes.

Senior public health advisor at the National Board
of Health and Welfare

Interview 2: Manager for a care home in Stockholm

Interview person 2 (IP2) has worked as a care home manager for the past 20 years and has a background as a nurse. IP2 is one of two managers for a large care home with around 300 residents, located in the City of Stockholm. There are two main units, one for persons with predominantly somatic illnesses (ca 100 residents) and one for persons with dementia (ca 130 residents). In addition, there are units for short-term and respite care, a unit for older persons with psychological conditions, day care services and an open meeting place for older people.

The two care home managers have seven deputy unit managers, each deputy manager is responsible for around 50 residents. The total number of staff is around 300, of which 160 have a permanent position and the rest are fixed-term employed or employed by the hour.

We first heard about the pandemic via media, in the beginning of January. That's when one started to think, what is this? At that time, we did not hear anything from the City of Stockholm or the district administration. It was more like, "take it easy, don't rock the boat, this will probably not come to Sweden".

In February, when people started to understand more, we [i.e. care managers] had a first meeting with the district director, who wanted to hear about the situation and availability and need for PPE. Me and a colleague, who also is a nurse, realized that now is the time to order PPE, as much as we can get. As nurses we are trained for crisis situations. Some colleagues thought that we should calm down a bit and seemed to think, like many people in general did at that time, "this will probably not be such a big danger". The medically responsible nurse in our district agreed and teamed up with us and said, "this will definitely come to Sweden". /.../

Then it was the winter holiday [February 24-Mars 1], and people would come back from their holidays. Our staff come from all over the world. We knew that several staff would be coming home from Iran, where the pandemic already had started. Other staff members from Iran described the situation there as a "disaster with many sick and dead", which strengthened our concern. And that

raised an urgent question: how should we handle staff returning from countries with COVID-19 outbreaks? At that time, no tests were available, so we decided that they should stay at home and see if they got sick. We also received indications from the region that there would be a lack of PPE. We ordered PPE from our supplier, but they could not deliver to us because the region [i.e. the health care] was prioritized, that was stressful. /.../

On March 13, we had the first infection at the facility, we thought, “now it’s for real”.

Manager for a care home in Stockholm region

IP2 emphasizes that they are lucky to have a very high level of nurse staffing to be a care home. Once the first resident was infected by COVID-19, we immediately rearranged the care and a range of measures were taken. We started cohort care, hired a lot more staff and virtually closed down the building so that no staff had to go between the wards. We had great support and collaboration from the district administration, who took over some of our administrative tasks, for example, staff recruitment, so that the care managers could work more operationally, closer to the staff. The need for staff became even greater because some staff members were too scared to work due to COVID-19 and some staff belonged to an at-risk group.

Although this is such a big care home in terms of number of residents, they have had very little infection, which has received attention in the City of Stockholm. IP2 identifies some key factors behind that they have managed relatively well in comparison to many other care homes are that: they acted rapidly to secure the care and the supply of PPE; the district administration provided good support; they had a lot of staff, they were almost “overstaffed”, especially many registered nurses who are of most importance in the work with basic hygiene routines and who could closely supervise the assistant nurses. The backup of many deputy managers was a very important support during these months. IP2 has talked to other care home managers in other districts, who haven’t had the same collaboration and support from their district administration, and thus not had the possibility to work in this way, they have not managed well, it turned out really bad, according to IP2.

Interview 3: Manager for a care home in a rural municipality in the Swedish countryside

IP3 has been manager for a care home since 2019 and has an educational background in public health. IP3 has experience of working in LTC in the City of Stockholm.

The care home is dedicated for persons with dementia and has 32 residents. The staff consists of around 40 permanent employees, most of them full-time. In addition, they have staff from the municipalities’ pool of substitutes. They strive, as far as possible, for permanent employments. The facilities are getting a bit old and are not optimally designed for this group’s needs.

Since the pandemic started, the municipality has had one COVID-19 related death, and a few cases in the care homes during spring 2020. In this specific care home, they have had one confirmed case of COVID-19, that person survived.

In January, I never thought it would affect us as it did. It felt like something big and dangerous, but far away. But step by step it came closer. Then the first Swedish case was confirmed, but still I thought it would not come to our small remote municipality. But that was not the case.

In mid-March, the municipality went into a state of readiness and banned visits to care homes. We closed down early, there was still no government decision on that. During that period, the news was dominated by the pandemic, with many cases reported in the Stockholm area. It became clearer and clearer how bad the pandemic was going to be. /.../

On May 21, the nurse at the care home called and informed me that the first resident was confirmed infected. It was the Ascension weekend [i.e. public holiday] and I was on vacation at another location. So, from distance I immediately gathered a staff group, a cohort group, that should work with the infected person, isolated from other residents and staff. We had talked about this scenario, so there was a plan and preparedness.

The cohort group consisted of five members of staff who worked around the clock. We were in constant contact, went through routines over and over and discussed how to do. The group came up with many solutions on things that no one had thought of before, the situation was completely new to all of us. They really used their competencies and skills. They did a fantastic job!

Manager for a care home in a rural municipality

IP3 describes that they undertook a range of measures to protect the residents. All relatives had to be informed that they had confirmed infection in the care home. When the first resident was infected, the medically responsible nurse decided that visors and other necessary PPE must be used in all work with the residents. The municipality has a specialist dementia nurse, whose time has been entirely devoted to pandemic-related issues, for example to secure the availability to PPE. We have had PPE from day 1. Thanks to her, we have not experienced any shortage of PPE at all. We soon realized that the usual ways to purchase material did not work. To a large extent it was the local traders and companies who helped us. For example, a local distillery and a car workshop switched their production over to making hand sanitizer and surface disinfection. Such a mobilization of the civil society would be hard to achieve in a big city.

IP3 highlights that the infection came later to their municipality. As the infection came later, they had a little more time to prepare, otherwise they probably would not have managed this well. There was a plan in place before the municipality had any infection. At an early stage, the municipality formed a “COVID-19 group” that provided support and had the overall responsibility.

3.3. Analyses and Discussion

The COVID-19 pandemic has meant an excess mortality in the population during the first half of 2020 in Sweden. Many older people have been exposed to the infection and about 70 percent of those who died had various forms of old age care. Since the end of spring 2020, there has been a consensus among responsible politicians and authorities that Sweden has failed to protect the elderly from the pandemic.

The focus of this paper has been on how Sweden has dealt with COVID-19 during the spring. What has been enablers and barriers to combat COVID-19, is still not known. New facts and data are presented over time, giving new evidence over the pandemic. Likewise, it is a matter of perspective - “top down” or “bottom up” – as illustrated by the interviews. Time and perspective are two determining factors, when analysing the consequences of COVID-19 in Sweden’s 21 regions and 290 municipalities and the possibility to reach generalisable conclusions.

The pandemic has entailed a historic “stress test” for the Swedish health care and public services, for elderly persons, and in general. It has revealed and put the spotlight on several weaknesses and shortcomings in the Swedish system. In a recent report, it is highlighted that Sweden’s complex authority governance structure has caused concrete problems in handling the COVID-19 situation. The decentralized crisis preparedness has led to that nobody has responsibility for the overall security of supply preparations that the state itself or state monopolies previously had. The absence of central coordination and a coherent national plan alongside with significantly different systems amongst the regions were pointed out as some of the problems in the political debate regarding access to medical equipment (Hägglund, 2020). As early as March, the lack of protective equipment (hand sanitizers, gloves, face masks, protective coats, visors) became apparent. The need for protective equipment and medical materials in the health and social care increased in line with the spread of the infection. Since the responsibility for having stocks for their own needs lies on respective region and municipality, there was no overall national picture of the situation in the country. In many regions and municipalities, stocks were small and insufficient, so they began to ration available equipment and prioritize the needs of hospitals. This in turn led to the recommendations when protective equipment was necessary in e.g. care homes being surrounded by strict conditions. During the first months of the pandemic, it became clear that Sweden lacked sufficient warehouses, organization, guidelines for the use of protective equipment in various care situations, logistics for warehousing and distribution.

The COVID-19 epidemic meant that shortcomings in working conditions in old age care were highlighted. Problems that were admittedly known and often pointed out in the past, but now this became clear. The need for more institutional places for older people, for example, has been a recurring discussion over the past decade. Deficiencies in employment conditions, staffing, training, language problems, and lack of

work management have been pointed out on several occasions (NBHW, 2020b; SALAR 2020b).

Staff turnover in home help services and in nursing homes is almost a chronic problem. This means that personal continuity is often low and that, for example, elderly people with home help receive help from an average of 16 different people during a two-week period (NBHW, 2019). The problems with a large turnover of staff also result in difficulties in recruiting staff with the desired skills. Some municipalities will therefore be forced to employ staff with insufficient training. The pandemic has shown that precarious employment conditions, lack of protective equipment and poor knowledge of care hygiene have contributed to the spread of infection and that staff have also become ill (Szebehely, 2020). It should also be added that most care homes in the country do not have the necessary equipment required for medical treatment (for example, equipment to be able to give oxygen and intravenous drips). There is also a general lack of access to medically trained staff around the clock.

The COVID-19 pandemic has also shown that the coordination and cooperation between health care and social services in the care of older people has major shortcomings. For the risk groups and those with LTC, there were general recommendations and instructions - care at home - avoid seeking hospital care. Doctors have a key role in assessing the patient and to initiate the proper treatment, but the support from doctors in care homes varied. The regions recommended the primary care that the physical doctor visits in the care homes should be limited. This was especially problematic when it came to whether the sick was to be sent to hospital, cared for at home or in their care home. Prescriptions and treatment instructions were given by telephone. If palliative care becomes relevant, this requires, according to the National Board of Health and Welfare's instructions, an assessment by two doctors (who know the patient), the patient and relatives; conditions that were often not met. This is behind the discussion about palliative care for COVID-19 patients being initiated too quickly and with an uncertain basis. This should have resulted in some patients receiving incorrect care, which led to an inevitable death.

The Swedish Public Health Agency's strategy regarding testing for COVID-19 was initially focused on active infection tracing, something that was abandoned in mid-March. Instead, patients who came to the hospital were tested first, then hospital employees, then those with community-leading occupations and only then staff in health and social care. Of course, municipalities and companies could buy tests from private companies. However, the Public Health Agency's recommendations of the PCR test to detect COVID-19 infection and infection tracing did not take off until June and July. The government advocated increased testing activities and promised to cover the costs. Representatives of SALAR have, however, criticized the Swedish Public Health Agency for not previously giving clear signals to the regions to increase the testing rate. The Swedish Public Health Agency believes, however, that the recommendations were clear enough, but that it also did not want to risk that healthcare was overburdened. In retrospect, however,

the Public Health Authority has admitted that testing of, for example, staff in elderly care should have been started earlier.

The pandemic has affected people, businesses, regions, and municipalities very differently. The weaknesses in the care system naturally appear different in the country's 21 regions and 290 municipalities. The weaknesses interact, affect each other and result in individual regional and local problem images, as illustrated in the interviews. Therefore, it is difficult to determine to what extent the spread of infection can be related to general and structural problems in healthcare and old age care. The problems exposed by the pandemic therefore need to be analysed in each region and municipality. This applies to collaboration between healthcare and old age care, where the problems can depend on individuals, organization, and management. Today's management model with a three-part structure - state, region, municipality - entails problems in terms of management, coordination, and efficiency in the Swedish care system. Governing and coordination of health and social care from a national level has for long been a challenge and ever ongoing debate in Sweden. This must be understood within the context of the decentralized structure with regional and local independence, which limits the central governments' possibilities to regulate the LTC system. Likewise, the regions have no authority to decide over municipal matters as well as municipalities have no authority to decide over the regions. Sometimes the Swedish structure of health and social care is portrayed as bundle of silos.

What consequences the pandemic will have in the long term for the institutional care of older people, remains to be seen. Of course, there are large variations between the municipalities, but in many municipalities, there have been great difficulties in preventing the infection from spreading. As described earlier, many municipalities are small in terms of population and where resources for old age care compete with resources for other purposes. Since the infection has spread unevenly across the country, it is also not possible to claim that Swedish care for the elderly has failed to protect the elderly in general.

In the public debate, many proposals for change have been put forward. One proposal is for the state (national government) to take over responsibility for healthcare from the regions. Another suggestion is that the regions should take over responsibility for old age care from the municipalities. Alternatively, that the regions "take back" the responsibility for care homes, i.e. to reverse the Community Care reform from 1992. The Swedish Medical Association has advocated stronger state control of health care, such as an overall national responsibility for the purchase and storage of protective equipment and a re-introduction of a national responsibility for the purchase and storage of medicines.

A recurring proposal is that the municipalities should have a statutory right to employ doctors. Many are also calling for stricter requirements for the regions' and municipalities' contingency planning. Several of these problems are being investigated and will form the basis for proposals for reforms and

improvements in Swedish health care and social services. The government has responded with a decision on large financial contributions the coming year, both to municipalities and regions in general, and earmarked state subsidies for health care and care for older people.

Already in May 2020, the government responded with a new initiative – a “boost for care of the elderly” (“äldreomsorgslyft”) – to improve working conditions for staff, competence raises, and make it more attractive to work in LTC. Employees in the LTC will be offered paid education and training during working hours. The government will finance the costs for the time the employee is absent for studies. The investment comprises a total of approximately SEK 2.2 billion during 2020 and 2021. The government initiative is supplemented with an agreement between the Swedish Association of Local Authorities and Regions (SALAR) and the Swedish Municipal Workers’ Union, that employees who take part in the programme should be offered a permanent full-time employment. All in all, the investment is estimated to lead to 10,000 new permanent positions for assistant nurses and care aids. In September, the government decided to add another SEK 1.7 billion to this initiative.

Whether there would be any significant changes in the structure, responsibilities, and financing of care for the elderly seems less likely. But even if no major structural changes in elderly care will be implemented, the need for general resource reinforcements in old age care has become evident and acknowledge by all political parties. One conclusion is that both health care and municipal old age care are underfunded and therefore regions and municipalities require the state to bear a greater share of the costs of health and old age care.

Whether the pandemic will have consequences for Swedish old age care remains to be seen. There are large variations between the municipalities, but many of them have had great difficulties in preventing the infection from spreading. Others managed quite successful to stop the infection spreading, something illustrated in our interviews. Many municipalities are small in terms of population and resources for old age care compete with resources for other purposes. Since the infection has so far spread unevenly across the country, it is not possible to claim that Swedish health care and services for elderly persons have failed to protect the elderly in general.

The hardships experienced during the COVID-19 spring have exposed some serious cracks in the Swedish welfare model and challenged the self-image. The social contract, that stipulates that the state has the responsibility for the welfare of the citizens, through generous publicly provided welfare programmes, from the “cradle to the grave”, seems to have eroded. Sweden as a modern, well-organized country, with high ambitions for the care of older people, where the cooperation between health care and social services has been an international role model, has thus had significant problems living up to its reputation.

AMENDMENT

The pandemic is not over. In time of writing, in mid-December 2020, Sweden experience a second wave of COVID-19. The number of persons affected with COVID-19 is rapidly increasing, so also the numbers of deaths. In November, the highest monthly death rate since 1918, was registered. Hospitals are reporting an increasing number of patients admitted to intensive care. Several municipalities report on new cases of older people with home help and in care homes with COVID-19 and the death toll among older people in care homes have reached the same level as in April. Many municipalities have issued strong recommendations against visits to care homes.

Both national and local politicians, calls for a more intensive testing and infection tracing, especially in care homes. The current problem is that the regions' test capacity is reported to hit the ceiling. The national strategy is now reviewed week by week, with new, stepwise restrictions, now also with local variations and temporary measures. One example is the ban of public gathering to no more than 8 persons. Bar and restaurants are not allowed to serve alcohol after 22 p.m. Colleges will temporarily be closed down during December. New restrictions are also announced to be presented regarding travelling during the coming Christmas holidays. The public debate has been preoccupied by the "the face mask" issue. The political opposition, groups of professionals, care personnel and many among the general public is stressing the government to explain and motivate why Sweden is not recommending face masks, when in public situations.

On November 24, the Swedish Health and Care Inspectorate presented results from their review of how the pandemic was handled in the spring 2020. The Inspectorate has inspected several care homes all over the country, checked medical records, done interviews (e.g. with Medical Responsible Nurses) and reviewed complaints from patients and families. The report entails a very severe critique of all 21 regions for their shortcomings, ranging from lack of preparedness, incompetence, slowness, and lack of cooperation with and support to the municipalities. The most detailed criticism was that in about one-fifth of the patient cases examined, no individual doctors' assessment had been made when the patient was prescribed palliative care, a more or less illegal (non)action in individual cases.

This report can be considered as a game changer. National media has condemned what has happened as "a historic care scandal". Local newspapers from regions all over the country have this news on their front page, with mostly humble administrators admitting to failures and apologizing. The sharp critique targets all regional health authorities, which are now required to report within less than two months how they will improve their care, to avoid similar situations in the future.

A week after the report was published, the prime minister referring to the Inspectorates report underlined that it was the regions who were to blame for the shortages in care homes for older people. This has further fuelled

the public discourse, now focusing on responsibility and accountability, for the failures. Almega, an employer organization, which represents all private care providers, states that the general spread of the virus in society is the main reason for the spread of COVID-19 based on data from the care homes they run. The Swedish Association of Local Authorities and Regions suggest that the government should enable contractual cooperation between municipalities and regions, regarding doctors' interventions (in care homes) when the municipality and the region find it appropriate. Further, they blame the government for acting too slowly regarding introducing the visit ban in care homes, poor support to the municipalities, regarding the provision with necessary PPE, and lack of guidance how the COVID-19 testing should be organized, targeted, and financed. Finally, the Swedish Municipal Workers' Union, stated that the spread of COVID-19 in care homes was clearly related to poor working conditions, such as employments by the hour and lower staffing levels.

Finally, in the middle December, the Corona Commission presented their report, focusing on and evaluating the Swedish strategy to protect "the old and frail". The report stated:

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.

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

The Corona Commission's report has set the stage for how to understand what happened in spring, what is happening now and what happen next with the COVID-19 pandemic. The report has identified structural shortcomings in old care, calling for a major overhaul of the Swedish welfare system for older people.

<https://coronakommissionen.com/>

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