

COVID-19 and people with disabilities

Assessing the impact of the crisis and informing disabilityinclusive next steps

Sweden



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1 Executive summary

Disability inclusivity of disaster and recovery planning

The references to people with disabilities that are found in core strategies or plans of COVID-management are mainly in the form of certain impairments being included in the national risk groups for severe COVID-19.

In the National Board of Health and Welfare's plan for any new outbreaks of COVID-19, there is a section regarding measures/organisations for people with disabilities. This section describes the current situation and future need for initiatives in the field of disability (as described in section 14.2).

Impact of the virus on mortality among people with disabilities

In the population in general, around 6 % of people have been infected with COVID-19. Among people with disabilities who have accommodation according to LSS, 7.8 % have been infected. Among people with disabilities who have personal assistance 5.2 % have been infected with COVID-19. The death rate in the population is 0.1 %. For people with disabilities, both with accommodation according to LSS and with personal assistance, the death rate is 0.3 %. The death rate among people with activity/sick compensation (i.e., 'disability pension') is 0.06 %. The majority of deaths have taken place in hospitals, followed by nursing homes.

Outline of key concerns about a disproportionately negative impact of the COVID-19 crisis on people with disabilities

The three most significant disproportionately negative impacts of the COVID-19 crisis on people with disabilities are as follows:

Insufficient and inaccessible information has influenced experiences of security among people with disabilities and their relatives (section 2.3) and led to relatives keeping their children home from school for fear that the child will be infected in their school environment (section 12.2).

Insufficient knowledge of staff and insufficient protective equipment has led to an increased risk of infection and death in residential care (section 3.1), which in turn has led to a restraining order of allowed visits (sections 2.3 and 4.1) and social isolation for people with disabilities.

There is a risk of care debt for people with disabilities, due to less access to care during the pandemic, (section 4.3) which potentially may have major effects on health and well-being.

Examples of good practice

Three examples of good practice in terms of government or other initiatives to avoid or mitigate a disproportionately negative impact of the crisis on people with disabilities are as follows:

The government has commissioned the Participation Authority to collect and present information on the specific consequences and challenges that the COVID-19 pandemic has so far entailed for children and young people with disabilities and for their families. This information is likely to have an impact on the continued management of COVID-19 and thus have an impact on people with disabilities and their situation (section 2.3).

Financial compensation is provided to people who work part-time as a personal assistant to a relative with whom they live in a household, in cases where the relative must refrain from other work outside the home in order to avoid infecting the person entitled to assistance.¹ There is also financial compensation for protective equipment for personal assistants in connection with COVID-19, as described in section 9.2.

Accessible information material about COVID-19, involving people with disabilities, are available in several forms. Information material and web training package for social services and municipally funded health- and medical care that aims to provide staff with basic knowledge for work in people of old age and disability care (section 4.4).

Recommendations and opportunities for change

Three key recommendations for using recovery planning as a chance to enhance disability rights and inclusion in light of the disruption and social change brought about by the crisis are as follows:

The National Board of Health and Welfare, whose role is to support health care and social services in the work with COVID-19² and support and coordinate the regions' emergency preparedness in health care, collects situation reports, which form the basis for various types of situation analyses which are then compiled in situation reports and plans. In the plan for any new outbreaks of COVID-19 that the National Board of Health and Welfare has produced, there is a section regarding measures/organisations for people with disabilities. This section describes the current situation and future need for initiatives in the field of disability.

The Swedish Post and Telecom Agency (PTS) addresses the need for a digital identification strategy that works for all, access to up-to-date and accessible public information and a need to increase digital competence. They suggest several steps to be taken, by the relevant authorities and actors.

Disability interest groups, such as disability rights and/or user's organisations, provide recommendations that the multidimensional issue of disability, and the needs of people with disabilities need to be addressed in pandemic management, meeting the need for both physically and informatively, communicative as well as attitudinal accessibility.

¹ https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler.

² <u>https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler/ersattning-for-skyddsutrustning-for-personliga-assistenter-i-samband-med-covid-19</u>.

2 Disability-inclusive disaster and recovery planning

Article 11 – Situations of risk and humanitarian emergencies & Article 4(3) – involvement of persons with disabilities

2.1 Commitments to disability in disaster management and recovery strategies

The main general COVID disaster management and recovery plans have been recommendations from the Swedish Public Health Agency on keeping physical distance and washing hands, staying home in case of symptoms of COVID-19 (and family quarantine in case of infection in the family), restricting social contact, etc. Since 8 January 2021, a temporary pandemic law³ applies as well as a so-called 'restriction ordinance' - which means that legally binding rules are introduced for gym and sports facilities, shops and malls as well as places for private gatherings.⁴

In Sweden, crisis information (disaster management/recovery strategies) from Swedish authorities is collected on the website 'Krisinformation.se'.⁵ Krisinformation.se provides state-of the art information about COVID-19 as well as other disaster management/recovery strategies (such as water shortages and forest fires). In a search with the search words 'disability' and 'disability' (impairment / disability) only six hits appeared. The hits concerned COVID-19 vaccination (4), accessibility (e.g. accessible telephone calls) (1) and general information (1). Although there may be more information in the individual documents, which the search function does not pick up, it is not possible without a closer reading of each individual document or website suggestion to find any additional references to people with disabilities in the disaster management / recovery strategies published.

The references to people with disabilities that are found in core strategies or plans of COVID-management are mainly in the form of certain impairments being included in what are considered risk groups for severe COVID-19.

The Swedish Public Health Agency describes various types of risk factors for COVID-19 where certain diseases and impairments (which may be considered a disability) are pointed out as risk factors, such as neurological diseases, stroke and dementia.

Other reports have pointed to people with psychiatric diagnoses as a risk group⁶ but they are not included in this list and are thus not seen as a risk group in the national guidelines that exist for, for example, financial compensation for reduced work ability.

2.2 Involvement of people with disabilities in disaster management and recovery strategies

The government has held meetings with the disability movement in two rounds (June and December 2020) to discuss the situation for people with disabilities and COVID-

³ <u>https://svenskforfattningssamling.se/sites/default/files/sfs/2021-01/SFS2021-8.pdf</u>.

⁴ <u>https://www.krisinformation.se/detta-kan-handa/handelser-och-storningar/20192/myndigheterna-om-det-nya-coronaviruset/restriktioner-och-forbud</u>

⁵ <u>https://www.krisinformation.se/</u>.

⁶ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-10-6975.pdf</u>.

19.⁷ There is nothing written about whether these meetings have had any significant outcome.

2.3 Disability impact assessments and research to inform disaster management and recovery planning

The Participation Authority⁸ is commissioned to collect and present information on the specific consequences and challenges that the Coronavirus pandemic has so far entailed for children and young people with disabilities and for their families.⁹ The assignment is carried out in dialogue with, among others, the disability rights organisations, and will be reporting in April 2021.

A national study is being carried out by the Centre for Psychiatric Research at the Karolinska Institutet.¹⁰ The researchers are studying the effects of the COVID-19 pandemic on persons who have or have had psychiatric symptoms such as depression, anxiety, substance abuse and obsessions.

FUB is an interest organisation for persons with intellectual disabilities (ID). They have conducted two surveys in connection with COVID-19. One survey was aimed at people with ID and one at relatives and deputies of people with ID who live in special accommodation according to the Law of certain support and services to persons with disabilities¹¹ (onwards referred to as LSS) for adults.¹² The surveys show that many who live in 'LSS-homes' have been hit hard by the municipalities' lack of crisis preparedness and inability to provide good support to the residents during the pandemic. Many relatives and deputies experience a total lack of reliable information about the infection situation in the 'LSS-home' and insufficient or non-existent information to relatives, deputies and the residents about infection control routines and protective equipment. Visitation bans and other restrictions have also been introduced (for example regarding leisure activities, going to the store and shopping for food, etc.) despite the fact that an 'LSS-home' is the person's own home and that it is therefore not possible to restrict visits from, for example, relatives and friends.

How much of these, and other potential, reports affect inform disaster and recovery planning is uncertain, as they are either ongoing or recent.

2.4 Use of disaster management and recovery planning funds

At the moment there are no national government funds that have been specifically allocated to strategies/programmes for a national recovery strategy moving on from COVID-19, that specifically addresses people with disabilities.

⁷ <u>https://www.regeringen.se/artiklar/2020/06/funktionshinderdelegation-med-fokus-pa-coronaviruset/;</u> <u>https://www.regeringen.se/artiklar/2020/12/dialog-med-funktionshinderdelegationen-om-covid-19/</u>.

⁸ The Participation Authority is a knowledge authority that promotes the implementation of disability <u>policy, https://www.mfd.se/</u>.

⁹ <u>https://www.mfd.se/vart-uppdrag/regeringsuppdrag/samla-in-och-presentera-information-om-de-konsekvenser-och-utmaningar-som-coronapandemin-hittills-har-inneburit/</u>.

¹⁰ <u>https://psykiskohalsacovid19.se/</u>.

¹¹ <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387</u>.

¹² <u>https://www.fub.se/wp-content/uploads/2020/11/Riksforbundet-FUB-Rapport-till-coronakommissionen-november-2020.pdf</u>.

3 Mortality connected to COVID-19 among people with disabilities

Article 10 – The right to life

3.1 Are official statistics available concerning the overall mortality rate of people with disabilities?

There are no official statistics available concerning the overall mortality rate of people with disabilities. There is a register,¹³ the death register, which reports mortality regarding the total population on a yearly basis. To find out mortality regarding specific population groups, this register needs to be combined with other registers such as the patient register (where impairment is reported) or municipal registers, where for example disability related services (e.g. according to the LSS law) or the Swedish Social Insurance Agency registers where granted personal assistance is registered.

3.2 Are official statistics available concerning the mortality rate of people with disabilities who have died from complications connected to COVID-19?

Yes, the National Board of Health and Welfare provides statistics on the number of people infected and dead in COVID-19, among people who have accommodation according to LSS, as well as for persons who have personal assistance. There are also statistics for people who receive activity and sickness compensation (compensation due to no or reduced ability to work due to illness / disability). However, there are no comparative figures for previous years, which makes comparisons impossible.¹⁴

Statistics for COVID- 19 *from 2020-05-13 up to 2021-02-17 Source: The National Board of health and Welfare ¹⁵	Infected*	Death*	Total
Activity/sick compensation (disability benefit)	n/a	149	263 133 (year 2020)
Accommodation according to LSS	2313	94	29609
Personal assistance	990	63	19027
Population in general ¹⁶	627 022	12598	10 327 589

Table 1. Statistics on death, related to COVID-19.17

¹³ <u>https://www.socialstyrelsen.se/statistik-och-data/register/alla-register/dodsorsaksregistret/</u>.

¹⁴ <u>https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statistik-00/statisti</u>

¹⁵ <u>https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-om-covid-19/statistik-om-covid-19-bland-personer-med-funktionsnedsattning/</u> Retrieved 2021-02-17.

¹⁶ Statistics from FHM <u>https://www.folkhalsomyndigheten.se/smittskydd-beredskap/utbrott/aktuella-utbrott/covid-19/statistik-och-analyser/bekraftade-fall-i-sverige/. Retrieved 2021-02-18.</u>

¹⁷ The Swedish Public Health Agency presents the number of deaths infected calculated on the basis of laboratory-confirmed COVID-19 cases that died within 30 days of a positive test result. The National Board of Health and Welfare's statistics are based on the cause of death certificate.

The statistics on deaths related to COVID-19 starts in May 2020, after the 'first wave'. Table 1 shows that among the population in general, around 6 % of people have been infected with COVID-19. Among people with disabilities who have accommodation according to LSS, 7.8 % have been infected. Among people with disabilities who have personal assistance 5.2 % have been infected with COVID-19. The death rate in the population is 0.1 %. For people with disabilities, both with accommodation according to LSS and with personal assistance, the death rate is 0.3 %. The pandemic does not appear to have had a negative effect on mortality for people with support according to LSS. In 2020, an equally high proportion of people with such support died compared with previous years and in the age group 70 years or older, it was even a lower mortality rate in 2020, compared with the previous year.¹⁸ There was a slightly higher mortality rate among people with personal assistance (0.1 percent) compared with other support measures according to LSS.

The death rate among people with activity/sick compensation (i.e., "disability pension") is 0.06 %. The proportion of deaths with COVID-19 is relatively low among people with activity compensation and sick compensation. The cause of the relatively low death rate in COVID-19 has not been investigated, but reasonable explanations are that people with these compensations has a relatively low average age (the benefit is granted to people aged 16-65), that they predominantly live in their own household and not in institutional housing, and that support may not include nursing and close physical contact (as the largest proportion have mental disabilities).

Persons with personal assistance live in ordinary housing whereas people with accommodation according to the LSS live in special accommodation, such as residential care. Table 2 below shows the place of death from COVID-19 of people with personal assistance and people living in accommodation according to the LSS.

Place of death (COVID-19) ¹⁹ *from 2020-05- 13 up to 2021- 02-17	Hospital	Care or nursing home	Private home/community	Missing information	Total
Accommodation according to LSS	75	16		0	94
Personal assistance	52		4	7	63

Table 2. Statistics on places of death.

As shown in Table 2, most deaths of people with disabilities who have accommodation according to the LSS-law or personal assistance have taken place in hospitals, where the person has received care due to COVID-19.

¹⁸ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf</u>.

¹⁹ <u>https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-om-covid-19-bland-personer-med-funktionsnedsattning/</u>.

4 Access to health

Article 25 – Health

4.1 Emergency measures

In a report²⁰ from 2020, the Swedish local authorities and regions have described the changes that the COVID-19 pandemic initially brought about regarding health care. The report shows that during the period March to May in 2020, the pandemic led to a significant reduction in various care activities and contacts, not only those relating to planned visits and treatments, but also parts of unplanned care. Thereafter, a recovery took place until the beginning of autumn, due to a period of lower spread of infection. The report shows that, despite the need for major restructuring with a focus on emergency care and patients with COVID-19, a large part of ordinary care has been able to be maintained. The planned operations and treatments decreased during the Spring by approximately 20 %, compared with 2019. At the beginning of October 2020, approximately 90 % of the operating volume that applied at the beginning of the year was performed.

The report also shows that the number of doctor visits in specialized care decreased by 36 % in April 2020, compared with 2019. In August, the difference was only 9 %, compared with the corresponding month last year. For return visits in primary care, the same pattern is found. The difference was at most 38 % in August compared to the previous year when the corresponding figure was 14 %. The same pattern was found for physical care contacts at the hospitals which decreased in the initial phase, while home visits and distance contacts increased. The number of inpatient care sessions, both planned and unplanned, decreased by 11 %, with variation between different diagnostic groups. For primary care, various data show that patients with chronic illness were highly re-visited and that patients with newly diagnosed anxiety or depression were re-visited or contacted to the same extent as before. However, the report does not explicitly say anything about people with disabilities, and about their situation in health care.

There is nothing specific written regarding people with disabilities in the National Board of Health and Welfare's instructions regarding COVID-19,²¹ to the health service, regarding, for example, triage.²²

COVID-19 *from 2020-05-13 up to 2021-02-17	In-patient care	Intensive care unit*	Death*	Total
Activity/sick compensation (disability benefit)	1364	226	149	263 133 (2020)
Men/women	716/648	134/92	96/53	112 350/150 783
-49 years	294	49	26	94 567

4.2 Access to hospital treatment for COVID-19

²⁰ <u>https://webbutik.skr.se/bilder/artiklar/pdf/7585-847-0.pdf?issuusl=ignore.</u>

²¹ <u>https://www.socialstyrelsen.se/coronavirus-covid-19/stod-till-halso-och-sjukvard/.</u>

²² <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/triage-arbetssatt-vardcentral-covid19.pdf</u>.

COVID-19 *from 2020-05-13 up to 2021-02-17	In-patient care	Intensive care unit*	Death*	Total
50-64 years	865	138	93	168 566
65- years ²³	205	39	30	n/a
Ethnicity	n/a	n/a	n/a	n/a
Population in general ²⁴	27 956	5079	12 598	10 327 589

Table 3. Hospital treatment for persons with activity/sick compensation.

Table 3 shows that 0,6 % of people with activity/sick compensation from the Swedish Social Insurance Agency (formerly called a 'disability pension', for persons up to 65 years of age) were in either in-patient or intensive care units between May 2020 and February 2021. Corresponding figures for the rest of the population are 0,3 %. There is thus a higher risk for people with disabilities and activity/sick compensation to be in hospital treatment due to COVID-19. For the population in general the risk of a COVID-19-related death is around 0,1 % while the risk for people with activity/sickness compensation is around 0,05 %. The risk of death in COVID-19 has thus been lower for people with activity/sick compensation (16-65 years of age) than for the general population (all ages), but there are certain risk factors, such as a higher risk for men as well as a higher risk for older ages.

4.3 Treatment for COVID-19 in congregate settings

There are no statistics available on the number of people with disabilities who were treated for COVID-19 inside care/nursing homes and other congregate settings and not admitted to hospital.

4.4 Public health promotion and testing during the pandemic

The information on the national sites, such as Folkhälsomyndigheten and Krisinformation.se provide easy-to-read information about COVID-19.²⁵ The information could also be read out loud, by a 'read-speaker'-function. However, the information is not provided in other accessible formats such as sign language. These sites concern mainly public health announcements and measures.

Swedish healthcare uses home-testing for COVID-19 to a relatively small extent, instead there are public testing spots where you can book an appointment for sampling in case of suspected COVID-19. The appointment is made via an e-service where you book an appointment for sampling.²⁶ Appointments are made primarily via e-service,

²³ Generally, this kind of compensation is replaced by retirement compensation at retirement age (65 years).

²⁴ Statistics from FHM <u>https://www.folkhalsomyndigheten.se/smittskydd-beredskap/utbrott/aktuella-utbrott/covid-19/statistik-och-analyser/bekraftade-fall-i-sverige/</u>. Retrieved 2021-02-18.

²⁵ <u>https://www.folkhalsomyndigheten.se/smittskydd-beredskap/utbrott/aktuella-utbrott/covid-19/informationsmaterial/lattlast/.</u>

²⁶ <u>https://www.1177.se/Orebrolan/sjukdomar--besvar/lungor-och-luftvagar/inflammation-och-infektion-ilungor-och-luftror/om-covid-19--coronavirus/lamna-prov-och-fa-provsvar-om-covid-19/lamna-prov-for-covid-19/.</u>

but it is also possible to call the health service to book a vaccination appointment.²⁷ Information about the booking system is available at 1177.se, where each healthcare region has its own site with information. There is no site with accessible information about appointments, aimed at, for example, people with disabilities.

There are information campaigns and material produced mainly with information about COVID-19 aimed at, for example, people with intellectual disabilities (film and written material) and people with autism spectrum diagnoses.²⁸ The Swedish Participation Authority has also produced films showing the challenges that a pandemic can pose for children with disabilities.²⁹ In these productions people with disabilities have been involved. Information material has also been produced that is intended to be used by staff in disability care regarding the reduction of the spread of infection.³⁰ Another initiative is 'digital forums' where staff in disability care and in care for people of old age can meet and discuss the situation and good practices.³¹

The National Board of Health and Welfare offers a web training package for social services and municipally funded health- and medical care that aims to provide new staff with basic knowledge for work with people of old age and in disability care.³² There is also a supplement to these web trainings, about preventing the spread of infection and using protective equipment. They also offer training in basic hygiene routines that are specially adapted to work in residential care and LSS-homes and housing provided according to the Social Services Act.³³ The training is designed to be used both during the pandemic and after. The National Board of Health and Welfare has also developed comprehensive support on how methods used within residential care for persons with disabilities can be adapted during the ongoing pandemic.³⁴ The material shows how residential care can minimize risk for, and inform about, infection and how they can secure staffing.

4.5 Impact of the COVID-19 crisis on access to health services for general or pre-existing physical or mental health conditions

The National Board of Health and Welfare has examined the number of visits and treatments in health care in Sweden.³⁵ The first COVID wave, March-August 2020, led to a total decrease of 14 % (-135,986) in visits to specialized care in March – August

https://skr.se/covid19ochdetnyacoronaviruset/socialtjanstaldreomsorgfunktionsnedsattning/digitalaf orumomcovid19.32717.html.

²⁷ <u>https://www.1177.se/Orebrolan/sjukdomar--besvar/lungor-och-luftvagar/inflammation-och-infektion-ilungor-och-luftror/om-covid-19--coronavirus/om-vaccin-mot-covid-19/vaccination-mot-covid-19-region-orebro-lan/#section-121418.</u>

²⁸ <u>http://media.beteendeanalys.nu/2020/03/Att-st%C3%B6dja-personer-med-autism-genom-oroliga-tider.pdf; https://www.autism.se/information_om_corona.</u>

²⁹ <u>https://www.mfd.se/inspiration/larande-exempel/inspirerande-filmer/barn-med-funktionsnedsattning--mitt-i-en-pandemi/</u>.

 ³⁰ https://skr.se/download/18.68e83f2a17206c0cd3a2fb8a/1589379479354/Checklista-SKR-Forhindra-smittspridning-covid19-LSSboende.pdf.
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³² https://www.socialstyrelsen.se/coronavirus-covid-19/utbildning-och-material-covid-19/.

³³ <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453</u>.

³⁴ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-11-7031.pdf</u>.

³⁵ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-11-7065.pdf</u>.

2020 compared with the corresponding period 2017–2019. The number of people who had to wait a long time for care increased during the same period, especially when it comes to planned operations and measures. The number of operations and measures in specialized care decreased by a total of 31 % (-90 037) in March – August 2020 compared with the corresponding period 2017–2019. This means that 3 out of 10 treatments were not performed. Of those who waited for surgeries and operations, most waited in orthopedics and general surgery. The proportion of patients waiting for visits and treatment increased most among people aged 70 and older.

The National Board of Health and Welfare's follow-ups³⁶ also show that visits to digital care providers have increased during the pandemic, while at the same time, there has been a reduction of emergency unit visits. Part of the reduction can be explained by a reduced need for care, as, for example, injuries and the spread of influenza have consequence of the Swedish Public Health Agency's decreased as а recommendations on limited social contacts. At the same time, the follow-up shows that every fifth person avoided seeking care despite the fact that they may have had a need and some regions and hospitals have reported a small number of detected cases of, for example, cancer, heart attack and stroke. For people who avoid seeking care even though they have a need, this avoidance can lead to serious consequences as there is a strong link between delay in diagnosis and reduced quality of life, health and survival.

The National Board of Health and Welfare has also follow-up information on psychiatric conditions and the collection of psychotropic drugs on prescription during the pandemic.³⁷ For the period February – June 2020, data show that psychiatric care in many places has largely been available as usual. During the pandemic, however, there has been a pronounced shift towards digital and telephone contacts, while physical contacts have fallen sharply. There has been a reduction in the reporting of new cases of psychiatric conditions during the pandemic. This decrease has also been reflected in new prescriptions for medicines. The National Board of Health and Welfare concludes that this is probably due to the fact that people have sought care to a lesser extent during the pandemic, but whether this may mean a pent-up need for psychiatric care in the long term is unclear at present. Of the visits that took place at psychiatric emergency rooms during the period, more of the visits led to enrolments in inpatient care compared with previous years.³⁸ This may indicate that people who have sought care have had more difficult conditions and that the visits have not been possible to avoid or postpone.

Funktionsrätt Sverige, an umbrella users' organisation for people with disabilities, has warned that the 'care debt' that accompanies the pandemic will have major consequences for people with disabilities, but that the extent of the consequences will be difficult to both predict and prevent based on the lack of relevant statistics regarding

³⁶ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-12-</u> <u>7089.pdf</u>.

³⁷ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-10-6975.pdf</u>.

³⁸ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-12-7076.pdf</u>.

the target group.³⁹ A survey,⁴⁰ conducted by Funktionsrätt Sverige, of how people with disabilities have experienced the ongoing COVID-19 pandemic shows that almost one in three have experienced that care or care interventions not connected to COVID-19 have been postponed or cancelled. Six percent have also experienced that the pandemic caused the supply of medicines to be delayed or absent.

4.6 Vaccination programmes

The guidelines related to access to health care are foremost about prioritization of the COVID-19 vaccine. The national plan for vaccination against COVID-19 describes which groups should be offered vaccination first (priority).⁴¹ The primary purpose of the vaccination in the first stage is to protect the groups most at risk of becoming seriously ill or dying from COVID -19.

In the first phase, which began at the end of December 2020, people living in special housing for the elderly or having home care under the Social Services Act were vaccinated, as well as staff in elderly care, health care and close household contacts, i.e. adults living with someone who belongs to that risk group.

In the second phase, people aged 65 and older will be vaccinated, of which the oldest are vaccinated first, followed by people with chronic diseases (defined as in the risk group, described in section 2.1.) and people with disabilities (who receive support under the LSS Act or have personal assistance), as well as health and care staff who are in close contact with those at risk.

The third phase concerns people aged 18–64 with a disease or condition that carries an increased risk of becoming seriously ill in COVID-19 (i.e. belong to the risk groups) and people with a condition that involves difficulty following the advice on infection control measures. This applies to people aged 18–59 who have a diagnosis of dementia or cognitive or mental disability. This also applies to people who live in socially vulnerable situations.

People with disabilities are referred to as a risk group in the national plan for vaccination against COVID-19 where it is described that 'In phase 3, vaccination against COVID-19 is recommended for everyone aged 60–64 years and for those who are 18–59 years old and have a or several underlying diseases or conditions that may increase the risk of serious illness. This also includes people aged 18-59 who for various reasons find it difficult to protect themselves against infection, for example people with dementia and cognitive or mental disability and people who live in socially vulnerable situations.'⁴² However, the persons of old age are the risk group that should primarily be given priority for vaccines.

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³⁹ <u>https://funktionsratt.se/wp-content/uploads/2020/05/Underlag-Corona-funktionshinderdelegationen-19-maj.pdf</u>.

 ⁴⁰ <u>https://funktionsratt.se/wp-content/uploads/2020/09/Novusrapport-Funktionsratt-Sverige-sommaren-2020.pdf</u>.
⁴¹

https://www.folkhalsomyndigheten.se/contentassets/43a1e203f7344a399367b816e2c7144c/nationell-plan-vaccination-covid-19-delrapport-3.pdf.

https://www.folkhalsomyndigheten.se/contentassets/43a1e203f7344a399367b816e2c7144c/nation ell-plan-vaccination-covid-19-delrapport-3.pdf.

5 Income and access to food and essential items

Article 28 – Adequate standard of living and social protection

5.1 Emergency measures

The government has decided on temporary financial compensation for people in risk groups who are at risk of becoming seriously ill from COVID-19.⁴³ The decision came in force on 1 July 2020, and lasts until (at least) 30 April 2021, and applies to those who have a job or are self-employed and who must completely or partially refrain from working to avoid being infected at work. The compensation applies to those who:

- have a job but a disease that involves a high risk of becoming seriously ill when they develop COVID-19; and
- lack the opportunity to work from home. It is also required that the employer is also unable to offer other work tasks within the framework of the employment, or that it is otherwise not possible to adapt the work situation at the workplace so that the spread of infection can be avoided;
- can present a medical certificate proving that you are in a risk group for COVID-19.

The risk groups that may be entitled to compensation are:

- 1. cancer with ongoing or recently terminated treatment, with the exception of hormonal adjuvant therapy (adjunctive therapy);
- 2. co-morbidity in more than one of the diagnoses of cardiovascular disease, hypertension, diabetes with complications, severe renal impairment or chronic liver disease with cirrhosis;
- 3. obesity and Body Mass Index (BMI) 40 and above;
- 4. a neurological or neuromuscular disease or injury affecting respiratory function;⁴⁴
- 5. adrenal insufficiency;
- 6. completed transplantation with ongoing immunomodulatory treatment;
- 7. immune deficiency conditions such as severe combined immunodeficiency (SCID), sickle-cell anemia, HIV with low CD4 levels, severe generalized conditions such as extreme underweight, high-dose or long-term treatment with cortisone or other drugs in doses that may increase susceptibility to infection and/or combined impairments which involves an increased risk of being severely affected by COVID 19;
- 8. chronic lung disease with significantly reduced lung capacity.

The government has produced a temporary regulation which means that an allowance, for risk of spreading COVID-19 to their significant others, can be provided to certain relatives of people in risk groups, including children and their parents.⁴⁵ The government has decided that people with Trisomy 21 (Down syndrome) may be entitled to compensation for risk groups. If a person has a close relative's allowance or is an assistant to a close relative with Trisomy 21, he or she can receive compensation if he or she must refrain from working to avoid infecting him or her.

⁴³ <u>https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler</u>.

⁴⁴ This may include people with Trisomy 21 (Down syndrome).

⁴⁵ <u>https://www.regeringen.se/regeringens-politik/socialforsakringar/atgarder-inom-sjukforsakringen-med-anledning-av-corona/</u>.

The government has also developed a temporary regulation in parental benefit so that parents of children who are, or recently have been seriously ill can stay at home to protect the child against infection by the virus that causes the disease COVID-19.⁴⁶

5.2 Impact of the COVID-19 crisis

The National Board of Health and Welfare follows the development of financial assistance during the COVID-19 pandemic.⁴⁷ Financial assistance has increased in 2020, and the number of recipients of financial aid has increased during the first eight months of the year compared with the corresponding period last year.⁴⁸ The increase is affected by rising unemployment, as the possibility of receiving benefits via the social security systems, such as unemployment benefits and benefits from social insurance, is linked to current and past performance in the labour market. This means that groups that have not established themselves in the labour market, or have only partially established themselves, have less financial protection than others in the event of, for example, unemployment or illness. Several industries that have been hit hard by COVID-19 are industries with many temporary jobs and where many who have been outside the labour market get their first job.

People with disabilities and reduced working capacity have a vulnerable position in the labour market, and in the event of economic instability they risk unemployment to a greater extent than others in the population. Data on financial aid is not reported with regard to disability but some people with disabilities, based on a presumed vulnerable position in the labour market, may be at risk of unemployment and in need for financial aid as other financial transfer systems provide a lower financial compensation than work.

Funktionsrätt Sverige (a user's organisation) has conducted a survey among people with disabilities which shows that almost one in five people state that their personal finances have been negatively affected due to the Coronavirus pandemic (17 %).⁴⁹ Among those who state that their personal finances have been negatively affected due to the Coronavirus pandemic, just over half have solved their everyday finances by using their savings (55 %).

⁴⁶ <u>https://www.regeringen.se/regeringens-politik/socialforsakringar/atgarder-inom-sjukforsakringen-med-anledning-av-corona/</u>.

⁴⁷ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-11-</u> <u>7001.pdf</u>.

⁴⁸ <u>https://arbetsformedlingen.se/om-oss/press/pressmeddelanden?id=94DED7B8BAE3D07B&pageIndex=2&year=0&uniqueIdentifier=Riket</u>.

⁴⁹ <u>https://funktionsratt.se/wp-content/uploads/2020/09/Novusrapport-Funktionsratt-Sverige-sommaren-2020.pdf</u>.

6 Access to transportation and the public realm

Article 9 – Accessibility

6.1 Emergency measures

On 10 January 2021, a new pandemic law was passed that will apply temporarily (until September 2021).⁵⁰ The law concerns, among other things, restrictions on public transport. In short, the law means that anyone who conducts public transport or domestic air traffic or is responsible for premises or areas that are intended for use by passengers in public transport or air traffic, must take COVID-19 control measures. Such regulations may include requirements for limiting the number of persons on means of transport or on premises or in areas intended for use by travellers, as well as limiting the time during which traffic is conducted as well as other measures to prevent the spread of infection.

People who travel by public transport where a seat ticket is not offered are recommended from 7 January 2021 to wear face masks during the times on weekdays when many people usually travel: 07–09 and 16–18. However, individuals who for medical reasons or due to certain disabilities cannot wear face masks are excluded from the recommendation.⁵¹

According to government restrictions,⁵² no more than eight people may attend public gatherings and public events. The police can cancel an event that has more participants. An exception is made, however, for funerals, which may have up to 20 participants. Anyone who violates the ban can be sentenced to a fine or imprisonment for a maximum of six months.

Shops, gyms and indoor sports facilities must calculate the number of visitors so that each person gets ten square meters. The maximum number for the total area of the business must never exceed 500 people. They must have clear signs that make it clear to visitors how many are allowed to stay in the room at the same time and must also take appropriate measures for people to visit the activity one by one, without company.

6.2 Impact of the COVID-19 crisis

The Pandemic Act,⁵³ as well as the Swedish Public Health Agency's advices on public transport, also applies to transport services (färdtjänst) offered to people with disabilities. The law and the advice mean that the operators themselves must assess what they should do to reduce the risk of the COVID-19 virus spreading. FUB (a user's organisation) has made a summary of answers from the regions regarding travel services and coordination / co-planning due to COVID-19.⁵⁴ The summary shows differences across the country - some regions have introduced solo driving or a maximum of two passengers per car while other regions have not introduced any

⁵⁰ <u>https://www.regeringen.se/48d0af/contentassets/be61e037907843518f7c41d490dd2e78/prop.-</u> 2020_21_79.pdf.

⁵¹ https://www.folkhalsomyndigheten.se/smittskydd-beredskap/utbrott/aktuella-utbrott/covid-19/skydda-dig-och-andra/om-du-planerar-att-resa/i-kollektivtrafiken/.

⁵² <u>https://www.krisinformation.se/detta-kan-handa/handelser-och-storningar/20192/myndigheterna-om-det-nya-coronaviruset/restriktioner-och-forbud.</u>

⁵³ https://www.regeringen.se/rattsliga-dokument/proposition/2021/01/prop.-20202179/.

⁵⁴ https://www.fub.se/rad-stod/det-nya-coronaviruset/fardtjanst/.

restrictions. Some regions also point out that the need for travel services has decreased significantly, and that people with disabilities have withdrawn their applications for travel services. The reduction may be partly due to the restrictions that have been introduced which limit the possibility of participating in various types of public gatherings and that both employment and leisure activities have decreased significantly during the COVID-19 pandemic.

7 Involuntary detention or treatment

<u>Article 14 – Liberty and security of person</u> <u>Article 15 – Freedom of torture or cruel, inhuman or degrading treatment or punishment</u> <u>Article 16 – Freedom from exploitation, violence and abuse</u> <u>Article 17 – Protecting the integrity of the person</u>

7.1 Emergency measures

The National Board of Health and Welfare and the Swedish Public Health Agency provide guidelines and support for the social services' and the municipal health services' preparedness for a general spread of COVID-19 or other similar infections,⁵⁵ as well as guidelines that can be helpful in the work of preventing infection from entering and spreading to special accommodation for older people.⁵⁶ These include special guidelines and regulations regarding visits to special accommodation. The regulations clarify the organisations' responsibility for enabling (COVID-19)-safe visits.⁵⁷

In order to prevent the spread of COVID-19, the Government has, by ordinance (2020:979)⁵⁸ authorized the Public Health Agency to temporarily ban visits to special accommodation for older people and in March 2020, a national temporary ban on visits to special housing for people of old age was introduced to prevent the spread of COVID-19 disease. The regulation applies until 31 May 2021. The ban can apply in a municipality, a county, or the whole country. A municipality or region can request a restraining order if there are special reasons. The person in charge of the operation may grant exemptions from the restraining order in certain individual cases, for example in end-of-life care.

At present, the Public Health Agency's follow-up⁵⁹ shows:

- number of municipalities with ongoing restraining order: 28;
- total number of municipalities that have had a restraining order: 66;
- total number of municipalities that have had a restraining order for more than one period: 47.

On 1 October 2020, the previous national visit ban on the country's nursing homes was abandoned and people in nursing homes were once again allowed to receive visits. From 21 November 2020, however, a new regulation came into force which gives the Swedish Public Health Agency the opportunity to, if other measures are not sufficient to reduce the spread of COVID-19, decide on a ban on visiting special housing for people of old age. The regulation expires at the end of February 2021.

⁵⁵ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-</u> <u>dokument/artikelkatalog/meddelandeblad/2020-3-6673.pdf</u>.

⁵⁶ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/samlat-stod-hindra-smitta-sarskilda-boenden-for-aldre-covid19.pdf</u>.

⁵⁷ https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/foreskrifter-ochallmanna-rad/2020-9-6935.pdf.

⁵⁸ <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/forordning-</u> 2020979-om-tillfalligt-forbud-mot_sfs-2020-97.

⁵⁹ <u>https://www.folkhalsomyndigheten.se/smittskydd-beredskap/utbrott/aktuella-utbrott/covid-</u> 19/information-till-varden/personal-inom-aldreomsorg/lokala-besoksforbud-pa-aldreboenden/.

The starting point is that support and services conducted in accordance with the Social Services Act (SoL), the Act on Support and Service for Certain Disabled Persons (LSS) or the Health and Medical Services Act (HSL) is voluntary, the individuals are thus required to consent to the measures proposed.⁶⁰ At the same time, the business must be conducted in a way that is safe and secure for the users, which may mean that the business needs to decide whether they should advise against visitors with reference to the risk of infection.⁶¹ The Infection Control Act (2004:168)⁶² provides support for certain measures to be taken against the individual's will to prevent the spread of infection. Infection control physicians have an overall responsibility for infection control work within the region and must collaborate with other authorities and health care personnel to prevent and limit outbreaks or the spread of infectious diseases.

7.2 Impact of the COVID-19 crisis

The Swedish Health and Care Inspectorate has become aware that in accommodation with special services in accordance with the Act on Support and Service for Certain Disabled Persons, LSS, general restraining orders and other restrictive measures have been introduced due to the COVID-19 pandemic.⁶³ As described in the paragraph above, the starting point is that care and support is voluntary and that measures must be based on respect for the individual's self-determination and integrity. In LSS, as in SoL and HSL, there is no support for taking coercive and restrictive measures, i.e. various forms of measures whose purpose is to restrict individuals or exercise coercion against them. At the same time, the business must be conducted in a way that is safe and secure for the residents, which may mean that the business needs to decide whether they should advise against visitors with reference to the risk of infection. Such a dissuasion cannot be equated with a ban. The Swedish Health and Care Inspectorate supervision of the spread of infection in special accommodation and services according to LSS⁶⁴ shows that it has often been a difficult adjustment for the residents. when restraining orders and other restrictive measures have been introduced. It has also been difficult that different kinds of activities have been restricted, such as day care services that have been closed due to the pandemic. The services describe that it has been difficult to create understanding among the users about the current situation. It has been a challenge to get the users to change or strengthen their hygiene routines and some users have become frightened and anxious when the staff wear protective equipment. To create understanding, the staff have worked to implement routines by preparing users for what is going on, informing and educating them with the help of image support, easy-to-read text and more.

To reduce the spread of infection, the organisation of Swedish regions and local authorities has produced a checklist aiming at reducing the spread in special accommodation according to LSS.⁶⁵

⁶⁰ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-11-7031.pdf</u>.

⁶¹ https://www.ivo.se/om-ivo/fragor-och-svar/faq-corona/#qa.

⁶² <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/smittskyddslag-</u> 2004168_sfs-2004-168.

⁶³ <u>https://www.ivo.se/globalassets/dokument/publicerat/iakttagelser-i-korthet/2020/tillsyn_lss_200527.pdf</u>.

⁶⁴ https://ivo.se/globalassets/dokument/publicerat/iakttagelser-i-korthet/2020/tillsyn_lss_200527.pdf.

⁶⁵ https://skr.se/download/18.68e83f2a17206c0cd3a2fb8a/1589379479354/Checklista-SKR-Forhindra-smittspridning-covid19-LSSboende.pdf.

FUB, an interest organisation for persons with intellectual disabilities (ID), have conducted two surveys in connection with COVID-19. One survey was aimed at people with ID and one at relatives and deputies of people with ID who live in special accommodation according to the Law of certain support and services to persons with disabilities⁶⁶ (onwards referred to as LSS) for adults.⁶⁷ The surveys show that many who live in 'LSS-homes' have been hit hard by the municipalities' lack of crisis preparedness and inability to provide good support to the residents during the pandemic. Many relatives and deputies experience a total lack of reliable information about the infection situation in the 'LSS-home' and insufficient or non-existent information to relatives, deputies and the residents about infection control routines and protective equipment. Visitation bans and other restrictions have also been introduced (for example regarding leisure activities, going to the store and shopping for food, etc.) despite the fact that an 'LSS-home' is the person's own home and that it is therefore not possible to restrict visits from, for example, relatives and friends.

FUB, on the basis of the surveys, states that people with ID and their relatives have been hit hard during the Coronavirus pandemic.⁶⁸ The FUB states that the pandemic has shown that not all people are valued equally and that the rights of people with ID are not seen as important. They highlight that their members give examples of situations, due to COVID-19, where the right to self-determination has been violated and when the basic principles of the equal value of all human beings have been negotiated or denied. FUB also point out that the situation for people who are already vulnerable has worsened during the pandemic when, for example, vital crisis information was not available, when decisions on distance education and school closures were made without considering the consequences for students with disabilities, when municipal (vocational and leisure) activities failed and not least when infection compensation for people at risk was delayed many months into the crisis. The FUB concludes that the COVID-19 crisis sheds light on the need for more control in the various parts of the public administration and highlights the shortcomings.

The same structural shortcomings that the Corona Commission⁶⁹ points out in care for older people are also found in the activities under the LSS, according to FUB.⁷⁰ These are crucial shortcomings in the staff's skills and competence, and managers with too many operations under them, which in practice means that they are more absent than present. Just as in care for people of older age, there is a high proportion of hourly employees and the problems within LSS have long been well known, which the National Board of Health and Welfare and the Swedish Health and Care Inspectorate, IVO, have been raising for many years. These shortcomings have become clearer during the pandemic based on the fact that the spread of infection is also a problem in 'LSS-homes'. A significantly higher proportion of people with ID (especially Down's syndrome)⁷¹ under the age of 70 have died of COVID-19, compared with the general

⁶⁶ <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387</u>.

⁶⁷ https://www.fub.se/wp-content/uploads/2020/11/Riksforbundet-FUB-Rapport-tillcoronakommissionen-november-2020.pdf.

⁶⁸ <u>https://www.fub.se/nyheter/fubs-rapport-till-coronakommissionen</u>.

⁶⁹ <u>https://coronakommissionen.com/</u>.

⁷⁰ <u>https://www.mynewsdesk.com/se/fub/pressreleases/fub-kommenterar-inom-lss-finns-liknande-brister-som-i-aeldreomsorgen-3060131.</u>

⁷¹ Bergman et al., (2021) Risk factors for COVID-19 diagnosis, hospitalization and subsequent allcause mortality in Sweden: a nationwide study. European Journal of Epidemiology. https://link.springer.com/content/pdf/10.1007/s10654-021-00732-w.pdf.

population, and they also have a greatly increased risk of becoming seriously ill or dying of COVID-19. The Corona Commission's proposed measures on, for example, requirements for minimum education and special educational initiatives in care for people of older age have an equal bearing on staff in LSS activities, according to FUB, as LSS-homes have a similar organisation. The FUB therefore calls on the government, at the same time as much-needed investments are made in care for people of older age, to implement strong measures to raise the level of competence in LSS activities.

8 Violence, exploitation or abuse

Article 16 - Freedom from violence, exploitation and abuse

8.1 Emergency measures

The municipalities have a statutory responsibility and obligation according to both the Social Services Act and regulations when it comes to meeting the needs of all crime victims' needs for support and help. A special responsibility concerns women and children who had experienced violence in close relations.

The Gender Equality Authority has been commissioned by the government to identify and develop effective methods for how municipalities can disseminate information about violence in close relationships and honour-related violence and oppression, as well as how contact can be established with victims of violence.⁷² They should also disseminate the methods to the municipalities. The implementation of the assignment shall be based on the special circumstances and conditions that prevail, due to the outbreak of COVID-19.

The Gender Equality Authority investigate,⁷³ among other things, whether there is information on exposure to violence in connection with the information on COVID-19 that the municipalities provide. In accordance with the government assignment, they investigate in particular information on exposure to violence for older women, people with disabilities, people who are exposed to honour-related violence and oppression, foreign-born women, HBTQ people and children.⁷⁴ Abuses that take place over digital media are also covered, as well as the area of prostitution and human trafficking. The inventory shows different examples in municipalities. Several municipalities have, among other things, improved their information on violence in close relationships, but in some municipalities, there is still a lack of information. This applies in particular to areas aimed at victims of violence, older people, people with disabilities and HBTQ people. Furthermore, information in different languages is sometimes missing. When it comes to information about violence in digital media and prostitution and human trafficking, there is a lack of information in a majority of the municipalities.

8.2 Impact of the COVID-19 crisis

The Swedish association of local authorities and regions (SKR) points to the risk that when more people isolate themselves at home due to COVID-19, the risk of violence in close relationships increases.⁷⁵ They also point to the risk that it will be more difficult for the vulnerable to seek help. From their view municipalities need to prepare for more people needing support and protection both now and after the pandemic, as the longer families are isolated at home, the greater the risk that women and children are exposed to violence in close relationships, honour-related violence and sexual violence.

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⁷² <u>https://www.jamstalldhetsmyndigheten.se/mans-vald-mot-kvinnor/covid-19</u>.

⁷³ <u>https://www.jamstalldhetsmyndigheten.se/mans-vald-mot-kvinnor/covid-19/checklista-till-kommuners-information-pa-webben</u>.

⁷⁴ <u>https://www.jamstalldhetsmyndigheten.se/mans-vald-mot-kvinnor/covid-19/checklista-till-kommuners-information-pa-webben.</u>

https://skr.se/covid19ochdetnyacoronaviruset/socialtjanstaldreomsorgfunktionsnedsattning/riskforokatvaldmotkvinnorochbarn.32700.html.

Anxiety, stress and financial insecurity may further increase the risk of perpetrators using violence.

Statistics from one of the police regions show that reports of violent crimes in the home environment have increased in a majority of municipalities during the Coronavirus pandemic.⁷⁶ During the period March to August this year, 14 % more reports were made in the county compared with the same period in 2019.

There are no statistics or reports on what it looks like for people with disabilities and the risk of violence during the pandemic, although issues related to being particularly vulnerable are highlighted in various writings about danger in the wake of COVID-19, as for example on the Gender Equality Authority's website.⁷⁷

⁷⁶ <u>https://www.svt.se/nyheter/lokalt/ost/vald-i-hemmet-har-okat-under-coronapandemin.</u>

⁷⁷ https://www.jamstalldhetsmyndigheten.se/mans-vald-mot-kvinnor/covid-19.

9 Independent living

Article 19 – Living independently and being included in the community

9.1 Emergency measures

People at risk who are at risk of becoming seriously ill with COVID-19 can apply for compensation if they must completely or partially refrain from working to avoid becoming infected. Compensation can also be applied for by people who work parttime as a personal assistant to a relative with whom they live in a household, in cases where the relative must refrain from other work outside the home in order to avoid infecting the person entitled to assistance.⁷⁸ The compensation is paid with a standard amount of a maximum of SEK 810 before tax per day for a maximum of 90 days.

The Social Insurance Agency provides compensation for protective equipment for personal assistants in connection with COVID-19.⁷⁹ The compensation can be paid to private companies and organisations that have a permit from the Swedish Health and Care Inspectorate (IVO) or to persons with disabilities who employ assistants themselves. Municipal organisers or those who, after agreement with the municipality, provide assistance cannot receive the compensation, as they already are compensated via the municipality or the region.

If an activity given according to LSS closes temporarily or if a user belongs to a risk group and therefore cannot be in that activity, the user may need a temporary extension of personal assistance hours.⁸⁰ In those cases, the municipality makes an individual decision. They are instructed that the applications need to be handled as quickly as possible to prevent the spread of infection to risk groups and to reduce anxiety among users and relatives. SKR has stated to the government that this may be an increased cost for the municipalities, which can apply for state subsidies for this in accordance with ordinance 2020:193 on state subsidies to regions and municipalities for additional costs as a result of COVID-19.

9.2 Impact of the COVID-19 crisis

No restrictions have been reported on personal assistance, which is the initiative that supports independent living for people with disabilities. Restrictions exist, of course, in opportunities to live a 'normal life' regarding, for example, community services based on the general restrictions that exist in Sweden, but they apply to everyone in the population. There are no data on how these restrictions have affected people with disabilities, but disability rights organisations⁸¹ have pointed out that people with disabilities can be affected more than others because many more participate in various employment measures (e.g. wage subsidies and sheltered workshops) and leisure

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⁷⁸ <u>https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler</u>.

⁷⁹ https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler/ersattning-for-

skyddsutrustning-for-personliga-assistenter-i-samband-med-covid-19.

https://skr.se/covid19ochdetnyacoronaviruset/socialtjanstaldreomsorgfunktionsnedsattning/funktion snedsattning.32905.html#5.67a0160b171871024beaf3e1,5.67a0160b171871024beaf404,5.67a01 60b171871024beaf3ab.

^{81 &}lt;u>https://funktionsratt.se/wp-content/uploads/2020/05/Underlag-Corona-funktionshinderdelegationen-19-maj.pdf</u>.

activities organised by municipalities, which have been negatively affected by the pandemic.

Persons who are 18 years and older and who receive interventions in accordance with the Act (1993:387) on support and service for certain disabled people (LSS), are judged to be a group with an increased risk of being exposed to infection and an increased risk of serious COVID-19, according to The Swedish Public Health Agency.⁸² This also applies to adults who have a decision on personal assistance compensation according to the Social Insurance Code (2010:110). There may be difficulties for these people to follow the advice to reduce the risk of being infected, e.g., among other things, taking into account that there are often more close contacts with staff, personal assistants and others.

Several of the assistance companies and other interest organisations for people with disabilities who have assistance have gathered information about COVID-19 for people with disabilities.⁸³

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https://www.folkhalsomyndigheten.se/contentassets/d4c81c0ca7814f79a61bb457d4baab49/nationell-plan-vaccination-covid-19-rekommendation-prioritering.pdf.

⁸³ For example: <u>https://www.intressegruppen.info/nyheter/artikel/corona-och-den-personliga-assistansen-information/</u>.

10 Access to habilitation and rehabilitation

Article 26 – Habilitation and rehabilitation

10.1 Emergency measures

A consequence of disruptions in health care due to COVID-19 may be that the care and vocational rehabilitation that people need to be able to return to their normal work is delayed. It can also affect people's right to sickness benefit according to the rehabilitation chain. The Government has therefore decided on a temporary provision that provides for the possibility of exemption from the ordinary time (testing of work capacity against regular work after day 180 and day 365) when applying for sickness benefit.⁸⁴ The exception applies to certain persons who are waiting for care or rehabilitation that has not been possible due to the Coronavirus pandemic and the strained situation in the health care system. The decision means that an insured person whose care and rehabilitation is delayed due to the effects of the disease COVID-19 must be exempted from the assessment of the ability to work. However, it shall apply up to and including the time when the planned care and rehabilitation has been completed.

The government has also decided to temporarily suspend work capacity assessments against ordinary work at the regular labour market after day 180.⁸⁵ The change applies retroactively from 21 December 2020. This means that those who have been on sick leave for more than 180 days have their ability to work tested against work at their employer instead of, as before, have working capacity assessed against a job that normally occurs in the labour market. This applies until the person has been on sick leave for one year.

The health care regions, which are responsible for habilitation efforts for people with disabilities, have to take into account current guidelines for reducing the spread of COVID-19.⁸⁶ This means that staff use the necessary protective equipment during individual visits. Courses, groups and lectures are cancelled or given digitally. It also means that visits need to be cancelled if someone, staff or patient, has COVID symptoms. There might be variation in health care regions' adaptation of measures, based on the regions being self-governing, and no collective information on this is available for the moment. There is also no collective information about which services have been affected as a result of these measures, but different regions address the impact of COVID in different activities such as habilitation services.⁸⁷

⁸⁴ https://www.forsakringskassan.se/privatpers/coronaviruset-det-hargaller/!ut/p/z1/hY9LD4IwEIR_iweu7GILabw1mIAIUeNB7MVAKA_FYIqQv-_z6GNu0_ImdwcEpCBUdm2qrG86lbX3eS-8A1uHNIxwmrDEpbhxFpyy0EHPJ7B7AvhFHEH8y4snQs057wQ-LIIAXOSbtUPoahpFW3wDP05EIKq2y1_vcpUTVoHQspRaanvQd7vu-4uZWWjh0I52OajTo5pG1VIbaqhKaSyjbTw04a6Mz2kP4NwOad4dNtrzCeTG9YXpzE!/?1dmy&urile=wcm%3apath%3a% 2Fcontentse_responsive%2Fnyheter%2Fnyhet-undantag-sjukforsakringen.

⁸⁵ <u>https://www.forsakringskassan.se/omfk/vart_uppdrag/om_socialforsakringen/rehabiliteringskedjan.</u>

⁸⁶ For example: <u>https://www.habilitering.se/om-oss/forandringar-pa-grund-av-coronaviruset/</u>.
⁸⁷ See for example:
https://www.elaria.co/dr22/citepapeta/claria.co/oran_factor_repport

https://www.aleris.se/4a7d73/siteassets/aleris.se/ogon/coronaeffekter_rapport_200928.pdf.

Habilitation units for people with disabilities offer customized information about COVID-19 and their operations at the unit, to their patients.⁸⁸

10.2 Impact of COVID-19 and/or emergency measures adopted

The pandemic has brought about changes for habilitation, not least in rapid digitalisation where many meetings and conversations with patients and relatives are now conducted remotely via telephone or video calls. Follow-ups have shown that many visits that were previously performed physically can now with good results be performed digitally with sound and image and save time especially for patients who do not need to go to a habilitation unit.⁸⁹ The focus in the work with the accelerated digitalisation has mainly been on individual solutions and adaptations. There are guidelines for what to think about digital meetings.⁹⁰

In the psychiatric clinics, however, there is a tendency for patients to have cancelled or rescheduled visits due to cold symptoms or fear of infection. Fewer patients have sought emergency psychiatric care and fewer have been admitted to round-the-clock care.⁹¹ At the same time, psychiatric clinics have reorganised and rebuilt to free up care places and be able to receive, care for and isolate patients who are infected with COVID-19. This means that there are more vacancies in adult psychiatry this year compared with recent years. The clinical staff foresee a great risk that the care seekers will increase when the infection situation in the country improves and that their problems have then become worse because they have waited to seek care. In this way, the pandemic will lead to a care debt to which resources must be allocated.

⁸⁸ <u>https://www.habilitering.se/om-oss/forandringar-pa-grund-av-coronaviruset/anpassad-information-om-coronaviruset.</u>

⁸⁹ https://resources.mynewsdesk.com/image/upload/fl_attachment/vvdbfyb0d4rmflc6650b.

⁹⁰ <u>https://www.digitalvardochomsorg.se/</u>.

⁹¹ https://resources.mynewsdesk.com/image/upload/fl_attachment/vvdbfyb0d4rmflc6650b.

11 Access to justice

Article 13 - Access to justice

11.1 Emergency measures

There is no information relating to access to justice available in relation to disability or older age.

11.2 Impact of COVID-19 crisis

There is also no information relating to the impact of the COVID-19 crisis on access to justice for people with disabilities.

12 Access to education

Article 24 – Education

12.1 Emergency measures

The Government may decide that pre-schools, schools, leisure centres or other activities in accordance with the Education Act shall be temporarily closed at national, regional or municipal level.⁹² If a principal closes a school following such a decision by the government, the principal has the opportunity to take measures in accordance with the temporary ordinance that was introduced in the spring of 2020. Schools that are open may in certain situations offer distance education to students who would normally have had on-site education.⁹³ It is also possible for principals to, for example, decide on outsourced teaching in other cases than what is possible with the ordinary provisions.

On 18 March 2020, Sweden's upper secondary schools (16-19 years) and municipal adult education (18 and above) were recommended to go over to remote learning.⁹⁴ The recommendation was then removed on 15 June due to the fact that the infection had decreased during the late Spring and Summer. On 23 November 2020, the government announced that upper secondary schools could, if necessary, go over to remote education. From Monday 7 December 2020, there came a directive on remote education for upper secondary schools and adult education that should continue until the Christmas break. After the Christmas break many schools started teaching on site although the Swedish Public Health Agency recommend remote education for upper secondary schools until 1 April 2021. The recommendation means that teaching shall be conducted as a combination of remote education and certain on-site education from 25 January to and with 1 April 2021. The recommendation does not apply to upper secondary special schools (for students with certain disabilities).⁹⁵ At the time of writing this report, COVID-19 infections have increased again in Sweden and many schools have announced that they are switching to have only remote education again, in order to reduce the spread of infection.

In April 2020, the National Agency for Education was commissioned by the government to support the school system during the pandemic.⁹⁶ The support has, among other things, consisted of publishing the World Health Organization's (WHO) international checklist for preventive advice in schools during the pandemic, reworked to Swedish conditions. The National Agency for Education has also developed Skolahemma.se,⁹⁷ which are support materials aimed at supporting schools to deal with the consequences of the pandemic concerning school activities.

⁹² <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2020148-om-tillfallig-stangning-av_sfs-2020-148</u>.

⁹³ <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/forordning-2020115-om-utbildning-i-vissa_sfs-2020-115" \o "länk till annan webbplats".</u>

⁹⁴ <u>https://www.skolverket.se/getFile?file=7657</u>.

⁹⁵ <u>https://www.skolverket.se/regler-och-ansvar/coronaviruset-och-covid-19---regler-for-skolor-och-forskolor/coronaviruset---fragor-och-svar-utifran-skollagstiftningen#h-</u> Delverme en detien en delviefierrellerdisteneuw den vieringformer and en viering former and en viering former and en viering former and en viering former and environment and

Rekommendationomdelvisfjarrellerdistansundervisningforgymnasieskolan.

⁹⁶ <u>https://www.skolverket.se/getFile?file=7657</u>.

⁹⁷ https://www.skolahemma.se/.

One of the Special Education School Authority's (SPSM) main tasks is to offer special educational support to preschools, schools and adult education. During the pandemic, SPSM reorganised its operations to meet changing conditions and the need for special educational support, which during the pandemic was predominantly given in digital form.⁹⁸ The pandemic has led to only a few special educational investigations being carried out, but advisory matters have instead been carried out via digital platforms. SPSM's experience is that the digital transfer has enabled closer contacts with those who receive support. However, in some cases, interventions have been terminated or moved to a later occasion due to the school's capacity or due to children or students being included in the risk group.

SPSM provides advice for distance education for various disability groups and during the pandemic, SPSM has created a knowledge portal for digital learning and support for distance education.⁹⁹ On their website, there are several new and updated support materials and study packages that aim to support the school to meet children, students and adults with disabilities. SPSM is also compiling an overview of how the pandemic is affecting its target groups and continues to follow the development in order to develop the special educational support.

12.2 Impact of the COVID-19 crisis

In mainstream primary school, the School Inspectorate report that the pandemic has affected both the opportunities to identify students' needs for support and the opportunities to offer students the extra adaptations and special support that they would normally have been given.¹⁰⁰ The report shows that the majority of the 106 principals, in the survey on which the report is based, feel that absenteeism among staff has affected the work of compulsory schools with extra adaptations and special support. This concerns the schools' opportunities to identify support needs, but also the opportunity to offer students the extra adaptations and special support that they are normally given. Support for learning is central to school legislation and it is therefore serious that several principals experience that this has been made more difficult during the current pandemic.

The majority of principals state that sick leave among the staff has affected the possibility of providing the support measures that students are normally given, both in form and scope. For example, some principals describe that students have not been given extra adaptations to the extent that they usually receive, because they have not had time to inform substitutes about all students' adaptations. In the cases where substitutes have had time to be informed, the principals see instead that the quality of the extra adjustments has been affected. Other principals give examples of staff who normally work with providing special support having to cover in classroom teaching or going on sick leave themselves, and that support measures have then been lacking for certain students. These are mainly special teachers and various forms of resource staff (i.e. teachers and staff who work with students with disabilities) whose skills and relationships with the students have been difficult to replace. According to some

⁹⁸ <u>https://www.skolverket.se/getFile?file=7657</u>.

https://www.spsm.se/sok/search/?page=3&querytext=covid&facets=&sortby=&hidesignupclosed=False&sitetags=.

¹⁰⁰ https://skolinspektionen.se/globalassets/02-beslut-rapporter-stat/granskningsrapporter/ovrigapublikationer/2020/covid-19/kartlaggnings-pm_dnr-2020-4850.pdf.

principals, the possibility of identifying and mapping support needs is also affected by sick leave among teachers and staff with special educational skills. Another group that is singled out as particularly difficult to provide support for are students who are dependent on a trusting relationship with certain staff and / or who have great concern about changes in general.

Among certain groups of students, the report shows that absenteeism is perceived to remain high.¹⁰¹ The report also shows that this applies, among other things, to students who belong to the special school's target group in primary and secondary school (i.e., students with disabilities). In almost all of these cases, it is a question of the students belonging to the risk group for COVID-19 or that the guardians are worried that the students will be infected. Some principals accordingly describe that they have worked actively to promote attendance and meet guardians' concerns by implementing adjustments in teaching and in organising the school day. For example, one of the principals has carried out more activities outdoors and another principal has arranged for students to have their lunch in a different place than in the dining room that is shared with the primary school. Other principals describe how they instead collaborated with guardians on homework for the special school students who are kept at home.

Riksförbundet Attention, a users' organisation for people with neuropsychiatric disabilities, has conducted a study on how COVID-19 affects the situation of people with neuropsychiatric disabilities (NPF) and their relatives. The study shows that already existing problems with the school have worsened for the target group on the grounds that the school does not meet students' needs, and there is a lack of support and adaptations which means that many students are not able to cope with the transition to distance studies.¹⁰² In the report's open text responses, it appears that the majority of the respondents experience a despair regarding remote education because the school is unable to adapt distance education. The open text responses testify that support efforts are non-existing and that remote education in practice means that the responsibility for the children's school results is transferred from school to guardians, which many parents feel they do not have the resources to cope with.

¹⁰¹ <u>https://skolinspektionen.se/globalassets/02-beslut-rapporter-stat/granskningsrapporter/ovriga-publikationer/2020/covid-19/kartlaggnings-pm_dnr-2020-4850.pdf</u>.

¹⁰² https://attention.se/wp-content/uploads/2020/05/rapport_coronakrisen_pdf-1.pdf.

13 Working and employment

Article 27 – Work and employment

13.1 Emergency measures

As described in 5.1 the government has decided on temporary financial compensation for people in risk groups who are at risk of becoming seriously ill from COVID-19.¹⁰³ The decision came in force on 1 July 2020, and last until (at least) 30 April 2021, and applies to those who have a job or are self-employed and who must completely or partially refrain from working to avoid being infected at work. The compensation applies to those who:

- have a job but a disease that involves a high risk of becoming seriously ill when they develop COVID-19; and
- lack the opportunity to work from home. It is also required that the employer is also unable to offer other work tasks within the framework of the employment, or that it is otherwise not possible to adapt the work situation at the workplace so that the spread of infection can be avoided;
- can present a medical certificate proving that you are in a risk group for COVID-19.

The risk groups that may be entitled to compensation are:

- 1. cancer with ongoing or recently terminated treatment, with the exception of hormonal adjuvant therapy (adjunctive therapy);
- 2. co-morbidity in more than one of the diagnoses of cardiovascular disease, hypertension, diabetes with complications, severe renal impairment or chronic liver disease with cirrhosis;
- 3. obesity and Body Mass Index (BMI) 40 and above;
- 4. a neurological or neuromuscular disease or injury affecting respiratory function;¹⁰⁴
- 5. adrenal insufficiency;
- 6. completed transplantation with ongoing immunomodulatory treatment;
- 7. immune deficiency conditions such as severe combined immunodeficiency (SCID), sickle-cell anemia, HIV with low CD4 levels, severe generalized conditions such as extreme underweight, high-dose or long-term treatment with cortisone or other drugs in doses that may increase susceptibility to infection and/or combined impairments which involves an increased risk of being severely affected by COVID-19;
- 8. chronic lung disease with significantly reduced lung capacity.

The government has produced a temporary regulation which means that an allowance, for risk of spreading COVID-19 to their significant others, can be provided to certain relatives of people in risk groups, including children and their parents.¹⁰⁵ The government has decided that people with Trisomy 21 (Down syndrome) may be entitled to compensation for risk groups. If a person has a close relative's allowance or

¹⁰³ <u>https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler.</u>

¹⁰⁴ This may include people with Trisomy 21 (Down syndrome).

¹⁰⁵ <u>https://www.regeringen.se/regeringens-politik/socialforsakringar/atgarder-inom-sjukforsakringen-med-anledning-av-corona/.</u>

is an assistant to a close relative with Trisomy 21, he or she can receive compensation if he or she must refrain from working to avoid infecting him or her.

The government has also developed a temporary regulation in parental benefit so that parents of children who are, or recently have been seriously ill can stay at home to protect the child against infection by the virus that causes the disease COVID-19.¹⁰⁶

13.2 Impact of the COVID-19 crisis

The Public Employment Service's review shows that COVID-19 has led to increased unemployment and reduced employment in the entire population.¹⁰⁷ The review shows that in August 2020, 8.8 % were unemployed. It can be compared with 6.9 % the same month the year before. Analysts at the PES, as presented in the review, have calculated 10 % unemployment or more before the situation turns around. The situation has not least had effects for many with disabilities who need support, adaptations, or subsidies to be able to maintain work ability. The review also shows that the large influx of newly unemployed people during the Spring and Summer of 2020 meant that the authority was forced to redistribute its resources. Among other things, several so-called SIUS consultants (SIUS stands for Special Support Person for Introduction and Follow-up Support and is an exclusive measure for persons with disabilities) have had to work with receiving and enrolling new jobseekers instead of their usual tasks, with providing support to jobseekers who have special needs due to disability.

The review also shows that many employers do not have the opportunity to offer new employment. Partly because the business has been hit hard by the Coronavirus and forced to make cuts, but also because many employers in certain industries are unable to recruit due to the risk of spreading the infection. This may affect applicants who are seen to be in need of internships in a workplace (which may be the case for job seekers with disabilities), who have found it more difficult to find an internship. Partly because employers find it difficult to receive trainees at the workplace, but it is also difficult to find a supervisor who can provide a good introduction and the support that the jobseeker needs at the workplace. Another concrete problem that the Public Employment Service's review report is the trend of remote working, for those who need adaptations in their work situation. The Swedish Public Health Agency recommends that those who can work from home and in many workplaces, remote work has become the norm. At the same time, there are people who have special adaptations linked to their workplace that make it more difficult to locate work at home and where adaptations have major positive effects on the individual's opportunities to cope with their work.

Concerns about the spread of infection and increased homework have also contributed to the Swedish Public Employment Service noting that it has become increasingly difficult to find, for example, wage subsidy employment for persons with disabilities. The review shows that in the agency's budget forecast from July this year, the forecast for payment of wage subsidies is downsized for the full year by more than SEK 400 million and the authority expects not to be able to use almost one billion of the allocated funds for wage subsidies. All in all, the situation means that the Swedish Public Employment Service has revised down its forecasts of the number of people with wage

¹⁰⁶ <u>https://www.regeringen.se/regeringens-politik/socialforsakringar/atgarder-inom-sjukforsakringen-med-anledning-av-corona/</u>.

¹⁰⁷ https://www.funktionshinderpolitik.se/sa-paverkar-coronakrisen-arbetsmarknadsstoden/.

subsidies for a long time to come. The forecast from the end of July 2020, for example, estimates that 23 800 people will have a decision on wage subsidies for employment during 2020 which is 200 fewer than what the authority expected before the summer.

14 Good practices and recommendations

14.1 Examples of good practice

Good practice examples include the following:

The government has commissioned the Participation Authority to collect and present information on the specific consequences and challenges that the COVID-19 pandemic has so far entailed for children and young people with disabilities and for their families.¹⁰⁸ The assignment is carried out in dialogue with, among others, the disability rights organisations and will be reporting in April 2021. This information is likely to have an impact on the continued management of COVID-19, as the Participation Authority is the authority responsible for disability law issues and their suggestions for improvements may thus have an impact on people with disabilities and their situation.

Another decision by the government, which is likely to have a more tangible effect on the situation of people with disabilities, is the decision of compensation to people who work part-time as a personal assistant to a relative with whom they live in a household, in cases where the relative must refrain from other work outside the home in order to avoid infecting the person entitled to assistance.¹⁰⁹ Another decision that may also be important for this target group is compensation for protective equipment for personal assistants in connection with COVID-19,¹¹⁰ as described in section 9.2.

There are information campaigns and material produced mainly on information about COVID-19 aimed at, for example, people with intellectual disabilities (film and written material) and people with autism spectrum diagnoses.¹¹¹ The Swedish Participation Authority has also produced films showing the challenges that a pandemic can pose for children with disabilities.¹¹² In these productions people with disabilities have been involved. Information material has also been produced that is intended to be used by staff in disability care regarding the reduction of the spread of infection.¹¹³ Another initiative is 'digital forums' where staff in disability care and in care for people of old age can meet and discuss the situation and good practices.¹¹⁴

The National Board of Health and Welfare offers a web training package for social services and municipally funded health- and medical care that aims to provide new staff with basic knowledge for work in people of old age and disability care.¹¹⁵ There is also a supplement to these web trainings, about preventing the spread of infection and using protective equipment. They also offer training in basic hygiene routines that are

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¹⁰⁸ <u>https://www.mfd.se/vart-uppdrag/regeringsuppdrag/samla-in-och-presentera-information-om-de-konsekvenser-och-utmaningar-som-coronapandemin-hittills-har-inneburit/</u>.

¹⁰⁹ <u>https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler</u>.

¹¹⁰ <u>https://www.forsakringskassan.se/privatpers/coronaviruset-det-har-galler/ersattning-for-skyddsutrustning-for-personliga-assistenter-i-samband-med-covid-19</u>.

¹¹¹ <u>http://media.beteendeanalys.nu/2020/03/Att-st%C3%B6dja-personer-med-autism-genom-oroliga-tider.pdf; https://www.autism.se/information_om_corona.</u>

¹¹² <u>https://www.mfd.se/inspiration/larande-exempel/inspirerande-filmer/barn-med-funktionsnedsattning-</u> -mitt-i-en-pandemi/.

¹¹³ <u>https://skr.se/download/18.68e83f2a17206c0cd3a2fb8a/1589379479354/Checklista-SKR-</u> Forhindra-smittspridning-covid19-LSSboende.pdf.

https://skr.se/covid19ochdetnyacoronaviruset/socialtjanstaldreomsorgfunktionsnedsattning/digitalaf orumomcovid19.32717.html.

¹¹⁵ https://www.socialstyrelsen.se/coronavirus-covid-19/utbildning-och-material-covid-19/.

specially adapted to work in residential care and LSS-homes and housing provided according to the Social Services Act.¹¹⁶ The training is designed to be used both during the pandemic and after. The National Board of Health and Welfare has also developed comprehensive support on how methods used within residential care for persons with disability can be adapted during the ongoing pandemic.¹¹⁷ The material shows how residential care can minimize risk for, and inform about, infection and how they can secure staffing.

In order to inform about infection in an accessible way, the National Board of Health and Welfare, together with other authorities, has also produced support material about COVID 19 to be used for people with intellectual disabilities.¹¹⁸ They also provide links to accessible information about COVID-19.

But although these are good examples of information that could mitigate the effects of COVID-19 on people with disabilities, there is no clear evidence that they have had any effect.

14.2 Recommendations

A range of organisations has made recommendations for disability related reforms in light of the COVID-19 crisis.

In the plan for any new outbreaks of COVID-19 that the National Board of Health and Welfare published in September 2020, there is a section regarding measures/organisations for people with disabilities¹¹⁹ where the National Board of Health and Welfare assesses that the following initiatives may be relevant to strengthening social services' ability to effectively handle new outbreaks of COVID-19:

- continued dissemination of the support material produced by the authority, in the form of knowledge support, support for situation pictures, checklists, training and more, due to the pandemic;
- continuously ensure that the authority's support material is updated, accessible and adapted to the needs of activities for people with disabilities, as well as based on research and the best available knowledge about COVID-19, as well as to review the need for adaptation based on different scenarios;
- support the implementation of the authority's support materials in the measures/organisations. Offer targeted support to particularly affected geographical areas;
- highlight examples of successful methods from measures/organisations, to provide inspiration and support to others;
- have a continued dialogue with both national and local actors and networks about the current situation and need for support in measures/organisations for people with disabilities;

¹¹⁶ <u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-</u> 2001453 sfs-2001-453.

¹¹⁷ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-11-</u> <u>7031.pdf</u>.

¹¹⁸ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-11-7030.pdf; https://www.msb.se/sv/aktuellt/nyheter/2020/november/film-for-personer-med-intellektuell-funktionsnedsattning-om-minskad-smittspridning/.</u>

¹¹⁹ <u>https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-9-6886.pdf</u>.

• continue to publish statistics and carry out analyses of the COVID-impact on measures/organisations for people with disabilities.

The Swedish Post and Telecom Agency (PTS) highlights the importance of digital participation and sees that the need was even clearer during the pandemic and put at its peak when physical meetings were not an option.¹²⁰ They assess that the point has been reached where access to and the ability to use digital tools is necessary for participation in society. PTS believes that the experience from the pandemic has clearly shown that it is now time to take the next step where two important parts are the issue of digital identity and to gather strength in the measures by strengthening collaboration and taking a long-term perspective. Recommendations for people of older age and people with disabilities, who to a much greater extent than before have been referred to the digital range of community services, culture, media, education, digital payments, medical services during the pandemic, include the need for a digital identification that works for all, access to up-to-date and accessible public information and a need to increase digital competence. They suggest the following steps to be taken, by the relevant authorities and actors:

1	Digital identification			
2	Increased focus on up-dated and accessible information			
3	Increased use of digital systems in the public sector and their digital services			
4	Provide opportunities for persons with hearing loss to communicate in written			
	text with the health care services			
5	Provide better opportunities for remote/digital teaching for pupils/students with			
	disabilities			
6	Long-term and coordinated work for everyone's digital participation			

Disability interest groups, such as disability rights and/or user's organisations provide recommendations that the multidimensional issue of disability, and the needs of people with disabilities need to be addressed in pandemic management and in strategies regarding, for example, information and vaccination.¹²¹ In general, both recommendations and criticism point to problems that have existed before the pandemic, even if they have been accelerated by the progress of the pandemic and involve a systematic exclusion of people with disabilities by not meeting the need for accessibility, both physically and informatively, communicative as well as attitudinal accessibility.

For example, My Right, a user's organisation for people with disabilities, gives the following recommendations to enhance disability inclusion and equality in the aftermath of the pandemic:¹²²

¹²⁰ <u>https://www.pts.se/globalassets/startpage/dokument/icke-legala-dokument/rapporter/2021/uppdrag-digital-omstallning-till-foljd-av-covid/digital-omstallning-till-foljd-av-covid.pdf0.</u>

¹²¹ <u>https://www.fub.se/wp-content/uploads/2020/08/Rapport-enk%C3%A4t-till-personer-med-IF-om-covid-19-2020-08-13.pdf; https://funktionsratt.se/wp-content/uploads/2020/09/Novusrapport-Funktionsratt-Sverige-sommaren-2020.pdf; https://www.fub.se/nyheter/fubs-rapport-till-coronakommissionen/.</u>

¹²² <u>https://www.omvarlden.se/Opinion/debattartiklar/i-sviterna-av-covid-19-maste-vi-alla-ha-ett-funktionshinderperspektiv/</u>.

- 1. Ensure that interventions benefit people with disabilities on equal terms with others. Adapt goals and governing documents and ensure that organisations' formulations include the desired development for people with disabilities.
- 2. Think beforehand and use universal design. Arrange new environments, materials and activities so that they are accessible to everyone as far as possible.
- 3. Map how people with disabilities and the disability movement should be included, consulted and collaborated with.
- 4. Include questions about the situation of people with disabilities in data collections and evaluations and take stock of the situation of people with disabilities.
- 5. Have a twin track in the work of including everyone, regardless of functional ability. Twin track means that:
 - a) include a disability perspective in all activities (mainstreamed),
 - b) work with targeted special solutions (targeted) for groups and individuals.

It is about adopting new perspectives, but also about implementing activities based on common sustainability goals in the work with the Agenda 2030.

Taken together, these recommendations, from both authorities and disability right organisations, are about the fact that the disability perspective needs to be included in both statistics and the planning and implementation of various pandemic-related initiatives in society. It is mainly about making these initiatives available to all citizens, by being designed to meet the different needs of many and follow up on their effects/usability from a disability perspective. Accessibility and follow-up are thus the general recommendations that are given from a disability perspective, so that people with disabilities are not discriminated against and their human rights violated in the efforts made, and hence are disproportionately affected by the pandemic's negative consequences.

Another recommendation that is of the utmost importance is that respect for human rights must exist even during a pandemic. When it comes to, for example, how people living in institutional care have been denied the right to live an independent life and have not been allowed to decide for themselves if and when they are allowed to meet their next of kin, this is despite the fact that they have a legal right to do so. The human rights-perspective need to be highlighted and clarified, in order to formulate future guidelines for what should apply in these situations.

14.3 Other relevant evidence

Overall, it is difficult to find comprehensive information about COVID-19 related to disability. On the government's page for COVID-19 related information, the keyword 'disability' gives only 15 hits in the site's search function.¹²³ Several of the hits also concern the same page, albeit in the form of an updated document. Searches on the Swedish Agency for Participation's website, the authority that handles disability rights issues, the keyword COVID gives only 10 hits.¹²⁴

https://www.regeringen.se/regeringens-politik/regeringens-arbete-med-coronapandemin/?page=2.
https://www.mfd.se/sok/?q=covid&p=2.

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