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# **STIL and ILI on the situation on Sweden in response to the call “Protecting human rights during and after the COVID-19, Joint questionnaire by Special Procedure mandate holders.”**

 

STIL is a non-governmental organization by people with disabilities. We work for self-determination, freedom, and equal opportunities regardless of one’s ability. We call it Independent Living or equal citizenship. Personal assistance is a human right and a tool to live the life we want to live. Therefore we are also a nationwide, non-profit assistance cooperative.

Independent Living Institute, ILI, is an NGO, think tank and project platform within the civil rights movement Independent Living of people with disabilities (independentliving.org). Our guiding principles are self-respect, self-determination and empowerment.

We have gathered information and written answers to some of the questions in the joint questionnaire. Please, do not hesitate to contact us if you have any specific questions about the situation in Sweden or the responses given to the questionnaire. We are also contributors and signatories to the joint response coordinated by the Swedish Foundation for Human Rights, and we have tried to not repeat ourselves in this deepened report with a disability focus.

## Common questions

### Impact on human rights

**Please explain the impact of the pandemic on the enjoyment of human rights and what actions have been taken by the State to respect, protect and fulfil human rights?**

Generally, little systematic monitoring of human rights enjoyment is done in Sweden as a response to the Covid-19 pandemic. Sweden still has no National Human Rights Institution under the Paris Principles. Although the Government has made progress in their plans to establish an NHRI, no date has been set, nor has it been the immediate priority to monitor consequences for Humans Rights due to the pandemic. The last indication of the plans to establish the NHRI were in response to the UPR recommendations.[[1]](#footnote-1) Prior to the recommendations, many civil society organisations demanded action in response to the emerging pandemic in March.[[2]](#footnote-2)

One important area of reform is employment strategy. Prior to the pandemic, the Swedish Public Employment Service, has been cut significantly, including support to persons with disabilities requiring public support in support measures in employment and support to find employment. Now, many are registering in the service as unemployment is rocketing as a result of the pandemic and the effects on the economy. The effects strike harder on the rights and situation of persons with disabilities, and could partly have been prevented by not cutting the services.[[3]](#footnote-3)

The National Board of Health and Welfare have issued a priority guidelines for intensive care based on biological age. They say disability isn’t a factor they should consider, but in reality this affects many people with disabilities, since their biological age often are higher than the population at large.[[4]](#footnote-4)

The right to personal assistance has gone through cuts in the last few years, and although the Government is making some progress on the right to assistance for breathing and meals, much more is needed for the right to fully live independently in the community. The control of personal assistance limits the amount of people a person has to meet compared to elderly care or in-home service. Therefore, personal assistance is a good tool for prevention of infection of risk groups and people in general. Unfortunately, there is no de-institutionalisation plan or plan to reduce in-home service with personal assistance.

**Are there any measures put in place in your country following the pandemic which have had a limiting effect on human rights? If so, please list them, provide an explanation for their adoption and indicate the time-frame by which they will be lifted?c**

A Municipality decided not to provide in-home care for persons using their freedom of movement to temporarily reside in a different municipality than the one they normally reside in. The decision was overturned by an administrative court.[[5]](#footnote-5) However, the parliament has subsequently asked the government to legislate so that the measure taken by the municipality is legal.[[6]](#footnote-6) This is expected to be treated shortly by the government.

**a) Were these measures determined by law? If yes, please indicate the relevant legislation.**

Some new laws were passed, including classifying Covid-19 as a disease dangerous to the public, passing a law on closing of activities on the area of schools by extraordinary events in peacetime (2020:148). On 2 April 2020, the parliament decided on a law that enables the government or authority after delegation from the government to enact changes in the right to certain economic benefits in the social insurance act (2010:**110**), 2 chapter 5 a §, in bill (2020:189).

**Please describe whether responses to the pandemic by States, businesses, faith-based organizations or others actors have resulted in a rollback of human rights, including in relation to affirmative action, gender-equality, inclusion of persons with disabilities and LGBT persons, land rights of indigenous peoples’ or access to sexual and reproductive health services?**

The SALAR asked the government twice to be allowed to revoke or stop the execution of granted rights under the social services act and the act on support and service to some disabled people. The municipalities and government agencies are not yet decreasing services officially on a broad scale, however there is risk that previous cuts to employment, social security and disability specific benefits will strike harder on the situation of disabled people in need of support from society than the general population.

**What long-term impacts of the pandemic and its response measures are expected on the enjoyment of human rights?**

The impact on the economy will likely lead to a significant decrease of tax flowing into the public sector, thereby limiting tax payers money to cover support from society to the population in general, including and specifically disabled people in need of a lot of support from society.

**Please explain if economic recovery and financial assistance mechanisms to reduce the social economic impact of the measures adopted have been subjected to prior human rights impact assessments?**

No human rights assessment has been done openly or explicitly. However, support packages from the state have been directed to people risking losing their employment.

### Statistical information

**Please provide epidemiological data on COVID-19 infections, recovery and mortality rates in your country, region or locality, disaggregated by nationality, race, ethnicity, religion, membership of indigenous peoples, age, gender, sexual orientation and gender identity, income/poverty levels, disability, immigration status or housing situation. Which groups in your country have been disproportionately affected by COVID-19 and how can this be explained?**

There is relative success, with regard to deaths and rates of infection of person assistance users compared to institution care provided for elderly persons with disabilities. Personal assistance users have to a large extent been able to avoid covid 19 which is a result of their ability to organise their own assistance due to the funding model.[[7]](#footnote-7)

People with disabilities are overrepresented in the statistics compare to the population at large. Many people with disabilities belong to the risk group but couldn’t isolate themselves completely. There is reason to suspect that more people with disabilities than the population at large have been hospitalised, and therefore also tested for covid-19.

**Please provide age disaggregated data on persons infected by COVID 19 and the percentage of them living in care institutions for older persons. Please provide age disaggregated data on deaths caused by COVID-19 and the percentage of them who were in care institutions.**

Please see updated Statistics on The National board of Health and Welfare homepage: <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/>

**Please share any information and data on the availability of health services to ensure access to testing, personal protective equipment and treatment. Please specify to what extent supply issues, economic, social or other barriers have limited access to testing, personal protective equipment and health care services, in particular for persons belonging to particular racial or ethnic groups, indigenous peoples, older persons, persons with disabilities, LGBT persons, persons living in poverty or in situation of homelessness, migrant workers, or persons without legal residency status.**

The right to test personal assistants through publicly and non-publicly funded structures were delayed compared to other employment groups. Personal assistants were included in the prioritised testing only from the middle of May. People with disabilities were not included in testing until the beginning of June, unless they were hospitalized. More and more regions are now allowing for the testing of personal assistants.[[8]](#footnote-8)

The processes for guaranteeing protective equipment was slow. Users of personal assistance found it difficult to obtain protective gear and testing for SARS-CoV-2 for assistants. At present, more regions are managing provisions better. The National board of Health and Welfare is now responsible for distribution, but the organisation of the mandate took time.[[9]](#footnote-9)

### Protection of various groups at risk and indigenous peoples

**What measures have public authorities taken to protect high-risk populations from COVID-19, including: a) health care and social workers, b) older persons, c) other persons with a possibly reduced immune system such as indigenous peoples, or persons living with HIV, d) detained and incarcerated persons, including persons under state custody; e) persons living in care homes, f) children and adults living in institutions, camps, shelters or collective accommodation, g) persons with disabilities, h) homeless persons; i) persons living in informal settlements or overcrowded homes; j) refugees, IDPs and k) migrant workers.**

The National Board of Health and Welfare was given the task to identify risk groups for increased risk of particularly harmful disease progression in Covid-19. It was done, and the results are available.[[10]](#footnote-10) However, it is generally quite difficult to understand the reasons behind some qualifications for belonging to the risk group. One example is persons with intellectual disabilities in combination with a mobility impairment, for which there is no medical reason provided. The government has narrowed the scope in legislative proposals that are meant to direct economic relief to risk groups and persons close to them.

People belonging to the risk groups are strongly recommended to avoid social situations and stay at home. All people are encourage to wash their hands, stay at home when having symptoms and practice social distancing.

A national governmental authority has provided guidelines to personnel working with people with disabilities.[[11]](#footnote-11)

Accessible information about the virus are available, e.g. easy to read, sign language and different kinds of pictograms.[[12]](#footnote-12)

On June 17, the government appointed a national coordinator for the vaccination. The mandate includes to identify strategic roads to create preconditions for a national access to the vaccination against covid-19. The coordinator will contribute to international needs and processes. We reiterate the need for a disability inclusive perspective when the plans are formed, and that the plan includes all persons within residential and other institutions, as well as personal assistants to persons with disabilities.

**Can you inform us about particular measures taken to mitigate the impact of the COVID-19 pandemic for communities and groups subject to structural discrimination and disadvantage?**

The Government still has no de-institutionalisation plan for people with disabilities living in group homes or other institutional settings against their will or due to a lack of a real and informed choice provided by the communities. Emergency re-institutionalisation seems to be more likely, unfortunately, as the municipalities are calling for the possibility to stop personal assistance schemes necessary for independent and community living in line with the CRPD article 19.

Restrictions for visiting nursing homes for the elderly were introduced, which was not the case for people visiting each other in the majority society communities.

**What measures have been taken by public authorities to ensure continued provision of services, including food, healthcare, education, psycho-social assistance to persons in vulnerable situation, including a) older persons, b) persons with disabilities, c) LGBT persons, d) persons in situations of homelessness, e) indigenous peoples, f) victims and survivors of domestic, sexual and gender-based violence, g) human trafficking, h) discrimination, i) victims of contemporary forms of slavery, including forced labour, as well as h) child victims of sale and sexual exploitation?**

**Has there been any interruption of services, such as the closure of emergency shelters, food banks, or the disruption of health care or psycho-social services that has been of concern?**

There has been a re-prioritisation of rehabilitation clinics, sheltered workshops, dental practises and forms or health care institutions meant to meet the more urgent threat of covid-19. Regular health care has also been down-prioritized to give room for intensive care units.[[13]](#footnote-13)

Lack in accessibility and support in hospitals and general health care for some disabled people has become evident. Personal assistants are not allowed to follow the user into the hospital, and information on the situation at a personal level has been hard to obtain. If a person who owns and uses a respirator and needs urgent health care, the ventilators are not allowed into the hospitals, which is problematic as the hospitals do not always have cough assist machines.

### Social Protection

**Please provide information on implemented and planned adjustments to the social safety net in response to the crisis, to ensure that individuals who lost all or part of their income as a consequence of the pandemic have access to sufficient nutrition, housing, water and sanitation, health care, energy and other essential goods and services? How has the State ensured fair and equitable access to social safety net measures across lines of race, gender, sexual orientation and gender identity, membership of indigenous peoples, and others?**

The government are currently drafting an improved regulation that is meant to grant people of certain risk groups a right to stay at home from work to avoid risk of infection through a preventive sick benefit.[[14]](#footnote-14) The government has introduced many efforts to relieve people from getting sick or losing their employment and from economic losses.[[15]](#footnote-15)

On June 16, a policy proposal brief was circulated to some organisations and agencies for feedback. The proposal is meant to provide certain economic compensation to persons close to those in risk groups (narrower definition than that of the National Board of Health and Welfare)[[16]](#footnote-16) that do not go to work or can not work from home to avoid bringing the infection to the shared home of the person that belongs to a risk group. The proposal, however, was conditioned so that you had to work as a personal assistant under the state programme (assistansersättning) or have “närståendeersättning”, not work as a personal assistant in schemes provided by the municipalities or in any other work. The deadline for comments was on June 17, one day after the circulation of the proposal. ILIs reply and the government’s documents can be found in the link in the footnote.[[17]](#footnote-17)

**How has the State approached social protection of small entrepreneurs and for people whose livelihoods are based in informal economies, in particular persons working often informally, in agriculture and other traditional livelihoods, child and health care, domestic work, construction, restaurants, street vending, tourism or as sex-workers? What specific efforts have been made to assess and mitigate the relevant health and social-economic risks to these populations?**

Support to corporations and small entrepreneurs was faster than that to employees or people belonging to risk groups that are not sick.[[18]](#footnote-18)

### Participation and consultation

**What decision-making processes were used to adopt measures to respond to the pandemic? Did they include participation of local and decentralized authorities, including indigenous authorities, scientific experts, and civil society organizations?**

The response to the pandemic has proven again the insufficiency of the Swedish consultancy proceedings prior to legislative and budgetary changes. DPOs are not consulted efficiently and with motivation to the decisions taken, which should be regarded as in contravention of the obligation under the UN Convention on the Rights of Persons with disabilities, see articles 4.3 and 33.3 (and the General Comment no 7 from the UN Committee on the Rights of Persons with Disabilities).

### Internet

**The internet and social media were increasingly used for work, education, shopping for food and other goods, awareness raising sharing of information, freedom of expression, religious ceremonies, cultural and social interaction, consultation and political decision making. What challenges and obstacles has the pandemic highlighted in terms of access for all to internet? Has the recent situation given rise to increased violations of human rights, mobbing and bullying online? If so, how was this addressed?**

The increased Internet relevance in education, shopping, media, political participation has had many positive effects for many, including many persons with disabilities. However, many are still left out from participation due to a lack of infrastructure to enable digital competence and comfort. Some people, for example with intellectual disabilities, epilepsy or need with speech synthesis, are left out from using new digital tools for communication used in in-home schooling and distance education.[[19]](#footnote-19)

### Accountability and justice

**Could you kindly highlight key concerns in complaints received by national human rights institutions, ombudspersons, anti-discrimination bodies in relation to the COVID-19 crises and how they have been addressed?**

The Swedish system for Human Rights violations are generally built on the agencies responsible for a matter not violating Human Rights. The individual and some organisations may take legal action against entities that breach rights under the European Convention on Human Rights and Fundamental Freedoms, although large access to justice barriers exist and very few people use this possibility.

Economic, social and cultural human rights are harder to enforce through the legal system. We do not have a National Human Rights Institution in line with the Paris Principles or article 33.2 of the UN Convention on the Rights of persons with disabilities.

The Equality Ombudsman has started to receive complaints and requests for legal assistance as information, and treats the complaints with total discretion. Few cases are brought to a formal inquiry, and only a very few are taken to court. Little information is provided openly, and systematic analysis of cases take time for the authority to produce, and we know nothing on the intentions of the Equality Ombudsman to make such an analysis.

**Could you provide any account and statistics on the impact of the COVID-19 pandemic on the operation of the justice system, including law enforcement, the provision of legal assistance and the operation of courts? Which activities were temporarily suspended?**

**In which way have restrictions for public or private meetings impacted on the freedom of expression and assembly? Have persons taking part in peaceful protest been fined, detained, or prosecuted for breaking national restrictions imposed for public or private meetings?**

Violence and breaking up of peaceful manifestations have occurred. It remains unclear if anyone has been or will be prosecuted.[[20]](#footnote-20)

**Could you kindly share information on emergency regulations and COVID-19 response measures that may have been reviewed or suspended by national or constitutional courts in your country?**

A Municipality decided not to provide in-home care for persons using their freedom of movement to temporarily reside in a different municipality than the one they normally reside in. The decision was overturned by an administrative court.[[21]](#footnote-21) However, the parliament has subsequently asked the government to legislate so that the measure taken by the municipality is legal.[[22]](#footnote-22) This is expected to be treated shortly by the government.

## Questions by the Special Rapporteur on extreme poverty and human rights

**1. In accordance with the ILO Social Protection Floors Recommendation No. 202 (2012), a national social protection floor is conceived as a basic set of rights entitling individuals to basic social security guarantees for health care and for income security for children, older persons and those unable to work, in particular in cases of sickness, unemployment, maternity, and disability. Do the economic recovery plans adopted include measures towards making progress towards establishment or strengthening of a national social protection floor?**

No. The recommendation is unfortunately not used much in Swedish politics, legislative processes or monitoring of Human Rights.

**5. The human rights principles of participation, transparency and accountability require States to create and maintain mechanisms by which individuals can meaningfully and effectively contribute to, provide feedback on and claim redress from policy measures that affect their enjoyment of human rights. Were any mechanisms established to allow people living in poverty to participate in the design, implementation and assessment of economic recovery plans?**

Nothing in terms of redress or specific feedback has been created as a direct response to the pandemic. The referral system prior to national parliamentary or governmental bills continue, but in practise with much shorter time limits to respond, so that the system risks becoming too strained to fulfill its function properly. In the case of social insurance, the response time was one day. We are still lacking a National Human Rights Institution, and no temporary instance has been created to deal with covid-19 response related matters.

## Questions by the Special Rapporteur on the right to adequate housing

**6) Can you provide examples of any other measures taken or planned by national, federal, provincial or local Governments in your country to protect the right to adequate housing during the pandemic and in its aftermath?**

There is no plan for de-institutionalisation of disabled people, as the Government consider them closed. However, the elderly and groups of disabled people live in institutional settings despite the labelling by the Government. Emergency de-institutionalisation schemes should be introduced, which include shutting down institutional residences where people live and would prefer a community based setting, and setting up action plans for safe transition to housing in the community. Homelessness and negligent closing risks harming people, which must be avoided by systematic and individualised approaches.

June 18 2020, Stockholm and Härnösand, Sweden

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1. <https://www.regeringen.se/pressmeddelanden/2020/06/regeringen-svarar-fn-om-rekommendationer-om-manskliga-rattigheter/> [↑](#footnote-ref-1)
2. <https://lagensomverktyg.se/2020/oppet-brev-mr-institution-vard-namnet/> [↑](#footnote-ref-2)
3. <https://arbetet.se/2020/06/16/over-700-arbetsformedlare-far-jobba-med-kundtjanst/> [↑](#footnote-ref-3)
4. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/nationella-prioriteringar-intensivvarden.pdf> [↑](#footnote-ref-4)
5. <https://www.domstol.se/globalassets/filer/domstol/forvaltningsratten_goteborg/nyheter/dom-fr-5025-20.pdf> [↑](#footnote-ref-5)
6. <https://www.riksdagen.se/sv/dokument-lagar/arende/betankande/vistelsekommuners-ansvar-for-socialtjanstinsatser_H701SoU24> [↑](#footnote-ref-6)
7. Statistics about covid-19 among people with disability (in swedish): <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-om-covid-19-bland-personer-med-funktionsnedsattning/> [↑](#footnote-ref-7)
8. <https://assistanskoll.se/20200520-Hallengren-assistenter-priotestning.html>

   <https://www.folkhalsomyndigheten.se/smittskydd-beredskap/utbrott/aktuella-utbrott/covid-19/antal-individer-som-har-testats-for-covid-19/>

   <https://www.folkhalsomyndigheten.se/publicerat-material/publikationsarkiv/p/provtagningsindikation--misstankt-fall-av-covid-19/> [↑](#footnote-ref-8)
9. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/process-stod-till-kommuner-200408-covid19.pdf>

   <https://www.av.se/halsa-och-sakerhet/sjukdomar-smitta-och-mikrobiologiska-risker/smittrisker-i-arbetsmiljon/coronaviruset/>

   <https://www.socialstyrelsen.se/coronavirus-covid-19/socialstyrelsens-roll-och-uppdrag/> [↑](#footnote-ref-9)
10. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/identifiering-av-riskgrupper-covid19.pdf>. [↑](#footnote-ref-10)
11. [https://www.socialstyrelsen.se/coronavirus-covid-19/stod-till-personal-inom-socialtjansten](https://www.socialstyrelsen.se/coronavirus-covid-19/stod-till-personal-inom-socialtjansten/) [↑](#footnote-ref-11)
12. <https://www.mfd.se/vart-uppdrag/tillganglig-information-om-pagaende-smittspridning/> [↑](#footnote-ref-12)
13. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/nationella-principer-for-prioritering-av-rutinsjukvard-covid19.pdf> [↑](#footnote-ref-13)
14. <https://www.regeringen.se/remisser/2020/05/remiss-av-promemorian-tillfalliga-bestammelser-om-forebyggande-sjukpenning-med-anledning-av-sjukdomen-covid-19/> [↑](#footnote-ref-14)
15. <https://www.regeringen.se/regeringens-politik/regeringens-arbete-med-anledning-av-nya-coronaviruset/for-anstallda-och-arbetssokande-med-anledning-av-covid-19/> [↑](#footnote-ref-15)
16. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/identifiering-av-riskgrupper-covid19.pdf>) [↑](#footnote-ref-16)
17. <https://lagensomverktyg.se/2020/remissvar-forandringar-socialforsakringen-covid-19/> [↑](#footnote-ref-17)
18. <https://www.regeringen.se/pressmeddelanden/2020/03/krispaket-for-svenska-smaforetag/> [↑](#footnote-ref-18)
19. <https://www.pts.se/sv/nyheter/pressmeddelanden/2020/ny-rapport-visar-tydlig-digital-klyfta-mellan-olika-grupper-i-samhallet/>, released June 17 2020. [↑](#footnote-ref-19)
20. <https://www.svt.se/nyheter/lokalt/stockholm/polisen-upploser-manifestation-pa-sergels-torg> [↑](#footnote-ref-20)
21. <https://www.domstol.se/globalassets/filer/domstol/forvaltningsratten_goteborg/nyheter/dom-fr-5025-20.pdf>. [↑](#footnote-ref-21)
22. <https://www.riksdagen.se/sv/dokument-lagar/arende/betankande/vistelsekommuners-ansvar-for-socialtjanstinsatser_H701SoU24> [↑](#footnote-ref-22)