Sweden’s answers to questionnaire on the right of persons with disabilities to the highest attainable standard of health[[1]](#footnote-1)

Please provide information on existing or planned legislation and policies to ensure the realization of the right to health of persons with disabilities, including current challenges and good practices.

**1. Existing legislation and policies**

The overall national objective of public health policy in Sweden is to create conditions in society enabling the entire population to enjoy good health on the same terms. The objective of health and medical care policy is to offer the population needs-adjusted, accessible and effective care of high quality. Several of the government's initiatives regarding health care are expected to have positive effects in the development of disability policy. Investments in the areas of chronic diseases and mental illness aim at creating more equal care and thus contribute to better care for persons with disabilities.

*For more information:*<http://www.regeringen.se/pressmeddelanden/2016/12/satsning-pa-vard-for-personer-med-kroniska-sjukdomar-fortsatter/>

<https://skl.se/halsasjukvard/psykiskhalsa/overenskommelsenpsykiskhalsa.234.html>

The most important law regulating the provision of health care is the Health and Medical Services Act of 1982. The Act requires the county councils to promote the health of their residents and to ensure equal access to health care. The act applies to every citizen in Sweden, including persons with disabilities.

There is a maximum amount that citizens are required to pay for health care in a county. The high-cost protection for non-institutional health care can also be applicable if persons seek care in a county other than the one in which they live. The high-cost protection means that, for a period of twelve months, citizens pay a maximum of SEK 1,100 in total for non-institutional care visits, such as to a health centre.

The county council shall offer those resident in the county council or who are remitted pursuant to section 16 of the Population Act (1991: 481) and permanently reside there;

* + Habilitation and rehabilitation
	+ Assistive technology for persons with disabilities
	+ Interpreting services for children who are deaf or deafblind and adults that are hearing impaired.

The responsibility of the county council does not cover the habilitation, rehabilitation and assistance that a municipality within the county council is responsible for. Habilitation or rehabilitation as well as provision of assistance should be planned in collaboration with the individual.

*For more information:*<http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag-1982763_sfs-1982-763>

The Patient Act came into force January 1st, 2015. The purpose of the Patient Act is to protect the rights and interests of the patient. The law states that patients are to be informed about their illness and the kind of treatments that are available. Patients have the right to participate in all decisions about the care they will be receiving. Patients must also be informed where they can obtain the care that they need. According to the Patient Act, caregivers are required to provide the patient with all necessary information no matter who the patient is or what background he or she has. For example, a clinic may be responsible for offering written information or an interpreter so that the patient can fully understand exactly how an examination will be performed.

*For more information:*<https://www.1177.se/Stockholm/Other-languages/Engelska/Regler-och-rattigheter/Patientlagen/>

The Patient Act also states that when there are different aids for persons with disabilities available, patients should be given the opportunity to choose. The patient shall receive the chosen aid if it appears justified in the light of his or her needs and the costs of the aid.
*For more information:*<https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientlag-2014821_sfs-2014-821>

The Equality Ombudsman (DO) shall, among other tasks, provide advice and support to help enable those who find themselves being subjected to discrimination. The Equality Ombudsman’s work is governed by the Discrimination Act (2008:568). Disability is one of seven protected grounds of discrimination. The Discrimination Act prohibits discrimination in a number of different areas such as health and medical care.

*For more information:*<http://www.do.se/other-languages/english-engelska/>

In November 2017, the Swedish Parliament voted for prop. 2016/17:188 *National target and focus on disability policy*. The proposal emphasizes that disability policy is based on Sweden's international human rights obligations. As a consequence of this bill, the government has initiated a review of the national disability policy with a focus on describing the application of the universal design principle. The review will furthermore propose the design of a stable and long-term governance and monitoring system based on the new national target and the new focus. These proposals will include issues regarding health care for persons with disabilities.

**2. Challenges**

Despite the principle of equal health care in Sweden, some studies give examples of situations when health care is unequal for persons with disabilities. The National Board of Health and Welfare's studies show for example that women receiving interventions according the Law regulating Support and Service to Persons with Certain Functional Disabilities (LSS) run an almost doubled risk of dying in breast cancer compared with other breast cancer patients. Another example is that individuals with measures under LSS who have identified acute myocardial infarction, receive balloon enlargement (PCI) half as often as other myocardial infarction patients.

**3. Good practice**

The Sörmland county council has a habilitation centre with two coordinators in order to offer better and more coordinated care and support for adults with extensive and lasting disabilities. The county council offers:

* A healthcare centre with special knowledge about various disabilities
* Possibility of longer medical periods and to meet the same doctor each visit
* Increased collaboration between different professions, such as doctors, nurses, physiotherapists and psychologists
* Increased cooperation between various healthcare institutions, such as the municipality's health care, habilitation activities and specialist clinics
* Possibility of additional assistance in coordinating various efforts

This coordinated care targets, for example, persons with Down's syndrome, multiple disabilities, spinal cord eruption, developmental disorder, cerebral palsy (CP), acquired brain injury, autism diagnosis, progressive neuromuscular disease or rare syndrome.

*For more information:*

https://www.landstingetsormland.se/funktionshinder/Habilitering/SMO1/

***Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the exercise of the right to health of persons with disabilities in general, as well as with particular focus in the following areas:***

**1. Availability of barrier-free general healthcare services and programmes, which take into account all accessibility aspects for persons with disabilities**

Accessibility at health centres has been improved for persons with

disabilities. At the same time, some of the shortcomings found by the

National Board of Health in 2010 remain. The results show:

* + Physical accessibility is high in the investigated activities, and almost all healthcare centres are accessible to wheelchair users.
	+ Accessibility is not as good for persons with impaired vision, but has improved slightly since 2010.
	+ Accessibility is significantly poorer for persons with hearing impairment.
	+ The possibilities of communicating with healthcare centres have improved for persons with reduced communication skills.
	+ About 40 percent of health centres have translated all basic information into easy-to-read.

*For more information:*

<http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20487/2017-2-10.pdf>

**2. Access to free or affordable general healthcare services and programmes, including mental health services, services related to HIV/AIDS and universal health coverage**

**Dental care support for persons with disabilities.** If a person with a disability suffers from certain long-term diseases and disabilities, he or she will often need more dental care than others. The dental care is then charged for as medical care. This means that the fee may be included with other fees

for health and medical care, and thereby included in the high-cost protection

scheme for medical care. Not all dental care is covered by the benefit.

**Youth guidance centres** are available across the country for all persons under the age of 23. Visits are free of charge. At youth guidance centres, midwives, counsellors and doctors work. Young persons can, among other things, get advice on contraception, make pregnancy tests and tests for sexually transmitted diseases. More than half of Sweden's youth guidance centres have group activities for young persons with intellectual disabilities. A number of centres cooperate with schools for students with special needs.

*For more information:*http://www.youmo.se/en-GB/Seeking-help/Youth-Guidance-Centre-/

**3. Access to free or affordable disability-specific healthcare services and programmes**

For certain diagnosis, there are centres targeting persons with this diagnosis. One example is the ADHD Center (Attention deficit hyperactivity disorder) in Stockholm, which is a support and knowledge centre for families with children between the ages of 3-17 and young adults between the ages of 18 and 25. The services are free of charge and the centre belongs to Habilitation & Health in Stockholm County Council.

*For more information:*<http://habilitering.se/adhd-center>

**4. Access to free or affordable health-related habilitation and rehabilitation goods and services, including early identification and intervention**

Health related habilitation and rehabilitation is included in the Health and Medical Services Act, and covered by high cost-protection. The specialized habilitation is an area with special skills about disabilities and complements the health care that all residents in Sweden are entitled to. Specialized habilitation for children is accessible in every county and covers a lot of diagnosis. Specialized habilitation for adults is not accessible in every county.
*For more information:*<http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20487/2017-2-10.pdf>

Another aspect of rehabilitation and habilitation is assistive technology. The results from a study conducted by the National Board of Health and Welfare indicates that the prerequisites for equal prescribing of assistive technology are good for both children and adults. The National Board of Health also assesses that the design of the regulations allows for equal provision of assistive technology in the country. However, there are differences both within and between county councils, regions and municipalities regarding fees.

*For more information:*<http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20487/2017-2-10.pdf>

<http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20092/2016-4-1.pdf>

Please provide information on discrimination against persons with disabilities in the provision of healthcare, health insurance and/or life insurance by public or private service providers.

**1. Discrimination against persons with disabilities in the provision of healthcare**

The Equality Ombudsman (DO) receives complaints concerning violations of the Discrimination Act. In 2017 DO received 84 complaints from persons with disabilities who felt they had been discriminated against in health and medical care because of their disabilities. A complaint can lead to DO initiating a supervisory measure. In 2017 DO initiated 2 supervisory measures regarding disability and health/medical care. Both of them regarding lack of accessibility:

1. In one of the cases DO investigated Stockholm County Council's work based on the prohibition of discrimination in the form of lack of accessibility, and whether the notifier had been subjected to discrimination associated with disability. DO found that Stockholm County Council had taken reasonable measures of accessibility and had not violated the prohibition of discrimination.

2. DO also investigated the work of a healthcare company connected to a claim of lack of accessibility. DO found that the company had taken reasonable measures and had not violated the prohibition of discrimination.

*For more information:*<http://www.do.se/lag-och-ratt/stallningstaganden/tre-vardcentraler-i-stockholmsomradet/>

In a study on health and disability made by the Swedish Agency for Participation 2017[[2]](#footnote-2) nearly half of the responders said that they had felt discriminated against in contact with health care. In total 2 108 persons answered the questionnaire.

*For more information:*<http://www.mfd.se/stod-och-verktyg/publikationer/rapporter/rapporter-2017/rivkraft-18--halsa-kost-och-fysisk-aktivitet/>

**2. Health insurance and/or life insurance by public or private service providers**

Swedish parents may not always be able to subscribe a private insurance for children with disabilities. The reason is that an insurance policy never applies to anything that occurred before the person or (if it is a child) the parents signed the insurance. Congenital diseases and disabilities are therefore often completely excluded. The insurance contract law states that an insurance company may refuse to subscribe for insurance only if there are special reasons. The insurance companies often require that certain exceptions be entered into the terms.

*For more information:*<http://www.publicerat.habilitering.se/sites/pubhab.wklive.net/files/product-files/forsakring-for-barn-med-funktionsnedsattning.pdf>

<https://www.konsumenternas.se/forsakring/olika-forsakringar/om-barnforsakringar>

Please provide information on the observance of the right to free and informed consent of persons with disabilities regarding healthcare, including sexual and reproductive health and mental health services.

Persons with disabilities have the right to free and informed consent regarding health care, just as any other citizen. One exception is the possibility of compulsory care for a psychiatric patient. This is regulated by the law on compulsory psychiatric care. Everyone who is subject to compulsory care is still entitled to expect good care on equal terms. In order for someone to be subject to compulsory care, the person must be suffering from a serious mental disorder, hospital care must be required and the patient must be opposed to the care (closed psychiatric care) or needs to comply with special conditions for the provision of necessary psychiatric care (open psychiatric care compulsory). Approximately 12,000 people are cared for annually through this measure.

*For more information:*<http://www.notisum.se/rnp/sls/lag/19911128.htm>

https://www.socialstyrelsen.se/statistik/statistikefteramne/psykiatrisktvangsvard

If a person needs help to monitor his/her rights, there are different forms of support:

* + - A guardian representing an unauthorized person in a legal context.
		- If someone on account of illness, mental disorder, impaired state of health or similar relationship needs help in guarding his or her right, managing his property or caring for his or her person, the court shall, if necessary, decide on a good man for him or her.
		- If a person is unable to care or his property, the court may decide to hold a trustee for him or her. However, the court cannot decide upon a trusteeship if it is enough with a good man.

*For more information:*<http://www.notisum.se/rnp/SLS/LAG/19490381.htm>

<http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19332/2014-1-17.pdf>

According to the law on sterilization, sterilization cannot be performed unless the person requesting the measure has been carefully informed of the implications and consequences of the surgery and, as appropriate, of other possibilities for preventing pregnancy. The Act on Forced Sterilization, which included some persons with disabilities, ceased to apply in 1975.

*For more information:*<https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/steriliseringslag-1975580_sfs-1975-580>

Please describe to what extent and how are persons with disabilities and their representative organizations involved in the design, planning, implementation and evaluation of health policies, programmes and services.

The Swedish government has regular dialogues with the Disability delegation. The delegation consists of representatives of disability organizations, officials from the ministry and responsible ministers. The purpose of these regular dialogues is both information and discussion on current issues, initiatives and budget.
*For more information:*<http://www.regeringen.se/artiklar/2017/09/budget-i-fokus-vid-hostens-forsta-mote-med-funktionshindersdelegationen/>

Special councils, ”sakråd”, is another working method in the Government Offices, which is used to gather the knowledge and perspectives of civil society organizations in certain matters. An example in the field of disability was a special council regarding the UN recommendations on CRPD in January 2017.

*For more information:*<http://www.regeringen.se/sakrad/2017/11/sakrad-om-fns-rekommendationer-kring-konventionen-om-rattigheter-for-personer-med-funktionsnedsattning-crpd/>

According to a recent follow up by The Swedish Agency for Participation, every third governmental authority that answered the questionnaire had consulted with disability organizations at an overall level. Most governmental authorities who produce regulations have developed it in cooperation with disability organizations. One example of such consultation is the Council for Disability Affairs, which is appointed by the National Board of Health and Welfare and act as advisory bodies.

*For more information:*<http://www.mfd.se/uppfoljning/offentliga-aktorer/uppfoljning-myndigheter/#6>

The county councils are responsible for health care and medical care. According to a recent follow up made by The Swedish Agency for Participation, all respondent county councils and regions indicate that they have recurring consultations with the disability organization at an overall level. A majority of the county councils indicate that the consultation is based on a written agreement or equivalent. Most of the county councils who have such agreements have developed these in collaboration with the disability organizations. Approximately half of the respondent county councils and regions indicate that the consultation has been evaluated over the past two years. Every other has conducted the evaluation in cooperation with disability organizations.

*For more information:*<http://www.mfd.se/uppfoljning/offentliga-aktorer/uppfoljning-landsting-och-regioner>

1. A timeframe of 2-4 years is used throughout the document, older evaluations have not been included. [↑](#footnote-ref-1)
2. All the responders had one or several disabilities. [↑](#footnote-ref-2)