

The Swedish Disability Rights Federation

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rights of persons with
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Answers to the questionnaire on the right of persons with disabilities to the highest attainable standard of health

The Swedish Disability Rights federation is an umbrella organisation for 41 associations which together represent approximately 400,000 members. Our work is based on human rights. Our aim is everyone's right to function in all parts of society on equal terms. Our goal is a society for all.

- 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.**

Existing legislation

The existing legislation¹ is non-discriminatory. According to the Health Care Act (Hälso- och sjukvårdslagen), health care should be provided on equal terms and with respect for each person's needs. In accordance with the Patient Act (Patientslagen) patients should be given information about and the possibility to participate in decisions concerning their treatment. Discrimination is forbidden according to the Discrimination Act (Diskrimineringslagen).

¹ Hälso- och sjukvårdslag (1982:763) http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag-1982763_sfs-1982-763

Patientlag (2014:821) http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientlag-2014821_sfs-2014-821

Diskrimineringslag (2008:567) https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/diskrimineringslag-2008567_sfs-2008-567

However, sufficient statistics are not available with respects to the extent with which the Swedish health care system fulfils these requirements. The National Patient Enquiry (Nationella patientenkäten) does not have questions with respects to disabilities². In 2016, The Swedish Disability Rights Federation drew attention to the need to collect data concerning health care for persons with disabilities, to the Swedish Association of Local Authorities and Regions (SKL) who are responsible of the National Patient Enquiry. So far, no data has been collected on persons with disabilities. There are a few studies from 2010, 2011 and 2013 showing remarkable differences in medical treatment and survival rates in ordinary somatic diseases such as stroke, heart disease and diabetes. Most of them are referred in our Alternative Report 2011³.

We are deeply concerned that the Swedish health care system is not sufficiently accessible to persons with disabilities and that discrimination against persons with disabilities continues to occur. Our demands for better statistics and follow up studies are left unfulfilled.

Another concern is that Sweden is one of few countries which lacks a Patient Rights Act⁴. The Swedish Patient Act addresses obligations for municipalities and County Councils, but there are no consequences if they do not comply with the law. The law stipulates, for example, the right of access to information and the possibility to participate in decisions concerning one's health care. This paragraph is especially important for persons with intellectual disabilities or communication difficulties. But if you do not get sufficient information or are not given the possibility to participate in the decisions there is no regulatory body to turn to. One has no possibility to demand one's rights in accordance with the law.

Planned legislation

Sweden is busy implementing the directive on the accessibility to websites and mobile applications of public sector bodies⁵. We hope that this will have a positive impact for patients' accessibility to their

² <https://skl.se/halsasjukvard/patientinflytande/nationellpatientenkat.617.html>

³ Alternative Report: <http://funktionsratt.se/wp-content/uploads/2017/11/Funktionshindars%C3%B6relsens-Alternativrapport-2011.pdf>

⁴ Sweden, Malta and Bulgaria are the only countries in this comparative index that do not have any patient rights legislation. <https://healthpowerhouse.com/publications/euro-health-consumer-index-2016/>

⁵ DIRECTIVE (EU) 2016/2102 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 26 October 2016 on the accessibility of the websites and mobile applications of public sector bodies, <http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016L2102&from=SV>

own patient journals, possibility to perform web bookings and access to health apps recommended by a physician or other health care professionals.

During the spring the government plans to investigate the situation for persons who need dental care due to disabilities or disease. In Sweden, health care is highly subsidised, whereas dental care is not. Our hope is that it will lead to improved dental health care for persons with disability or chronic disease. However, at the moment, we do not know what issues will be addressed in that investigation.

2. 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:

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

The health care system presents a lot of barriers for persons with disabilities. However, there are very few public reports on the subject. We have not been able to find any reports after 2010⁶. The 2010 report shows that accessibility to health care was adequate for people with impaired mobility. It was worse for persons with impaired vision, hearing or communication difficulties. Information about sign language and other aides for communication was missing.

Our impression is that not much has changed since 2010. In some primary health care centres, the only way to make an appointment is still by phone, and information about appointments is still sent out by post. However, it is becoming more common that patients can handle appointments through the web. At some primary care centres, you can only register via a tablet or computer, with no aides for persons with impaired vision or cognitive disabilities. Not all persons with communication disabilities are getting the help they need to correctly describe their condition or to fully understand the information (pictures, sign language etc). Only a few County Councils offer translation service for persons with aphasia and other communication disabilities⁷. There is no legal possibility to give

⁶ Socialstyrelsen (2010), Tillgänglighet ur ett funktionshinderperspektiv – En undersökning bland socialkontor och vårdcentraler (not available on the web)

⁷ <http://www.taltjanst.se/>

power of attorney to somebody to have a look at your journal or parts of your journal, which means no access to health data for persons who need help with this.

- **access to free or affordable general healthcare services and programmes, including mental health services, services related to HIV/AIDS and universal health coverage;**

The general health care, including mental health services and services related to HIV is covered by public health insurance. However, the health care services for persons with mental illness have long been criticised for being insufficient. Sweden has a history of long queues to health care, and when it comes to psychiatric health care the situation is severe.

According to legislation the County Councils should provide specialised health care, such as psychiatric treatment, within 90 days. But far from every County Council fulfils that requirement. On average, 88 percent of the patients receive treatment within 90 days, but in some County Councils only 66 percent (adults) and 68 percent (children) of the patients get treatment in time⁸. For some, it means that they must wait many months. This is devastating, especially for children and teenagers. Since the law is not a patient rights legislation there is not much a patient can do other than wait.

- **access to free or affordable disability-specific healthcare services and programmes;**

Some County Councils have started to introduce primary care centres specialised in health care for persons with intellectual or other disabilities. This does not follow the principals of universal design and might decrease the freedom to choose health care supplier for persons with disabilities. This trend is rather new and it is too early for us to evaluate.

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

Rehabilitation and habilitation is covered by public health insurance. The maximum cost per 12 months is 1 100 SEK. However, we have no statistics regarding access to health-related habilitation and

⁸ <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20872/2018-2-16.pdf>

rehabilitation⁹ only testimonies from our member organisations. Some, especially adults, with an autism spectrum disorder or ADHD diagnosis, have difficulties to get necessary rehabilitation and habilitation. Another example concerns persons with Parkinson's disease, who do not receive sufficiently rehabilitation to keep the disease in check.

When it comes to early identification and intervention there are a few studies from 2011 and 2013 showing that persons with mental illness and intellectual disabilities have much higher death rates, in ordinary diseases such as stroke, heart disease and diabetes¹⁰. For example, women with intellectual disabilities have 70 percent higher risk of dying from breast cancer than others. The reasons for those higher risks are many. We know that the information on regular control for breast cancer or cervical cancer do not reach women with intellectual disabilities. They also lack knowledge and accessible information on what they can do themselves, for example, to search for lumps in their breasts. This all means that they encounter the health care system much later than others. When it comes to persons with mental illness, the follow up system, to make sure there is compliance, is not good enough. These studies also show that there is discrimination of persons with mental illness. Unfortunately, there have not been any follow up studies or other national collection of data on this subject.

3. 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.

⁹ On these pages most of the statistics concerning health care in Sweden is collected.
<https://skl.se/ekonomijuridikstatistik/statistik/hittastatistik.264.html>
<http://www.socialstyrelsen.se/statistik>

¹⁰ Here you find links to a couple reports about mental illness and somatic disease:
Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom – hjärtinfarkt
Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom - diabetes
Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom - stroke
Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom – cancer
<http://www.socialstyrelsen.se/publikationer2011/2011-6-15>
Here is another report on higher risk of dying from cancer for persons with disability:
Socialstyrelsen (2013): Tillståndet och utvecklingen inom hälso- och sjukvård och socialtjänst – Lägesrapport 2013
<http://www.socialstyrelsen.se/nyheter/2013februari/funktionsnedsattaloperfordubbladriskattdoicancer>

There is a lack of current data or research on discrimination against persons with disabilities in the provision of health care. A report from The National Board of Health and Welfare (Socialstyrelsen) 2010¹¹ shows that the use of medication for depression, anxiety, sleeping disorders, schizophrenia etc, is three times more common among persons with retardation and/or autism spectrum disorder state than in the rest of the population. Every fifth person in the group examined is using medicine for schizophrenia or psychoses (neuroleptic). In the rest of the population the number is one percent. It is also more common that persons with these disabilities have older medicines with higher risk of side effects and epileptic seizures. The National Board of Health and Welfare (Socialstyrelsen) have also made a couple of studies (2011) that shows that persons with mental illness are more likely to get less effective pharmaceuticals and medical treatments than others. Unfortunately, there has been no reports or studies to see if there have been any changes¹².

According to the Insurance Contract Act (Försäkringsavtalslagen)¹³ insurance companies can exclude a person from getting an insurance, for example, if the applicant has a disease, that the insurance company deems could cause a risk for future problems. At the same time, it is forbidden to discriminate, according to the Discrimination Act (Diskrimineringslagen)¹⁴. This has led to a couple of court cases. For example, in 2015 a woman wanted to get a private health insurance for her daughter who is deaf. The insurance company refused because the mother receives care allowance under the Act on Disability Benefits. The case went to court and the insurance company was sentenced for discrimination¹⁵. Even though there have been a number of similar court cases during the last years, people are still excluded from private insurances, get a less comprehensive insurance or have higher insurance fees. This is a

¹¹ Socialstyrelsen (2010), Alltjämt ojämligt! Levnadsförhållanden för vissa personer med funktionsnedsättning <http://www.socialstyrelsen.se/publikationer2010/2010-6-21>

¹² Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom – hjärtinfarkt.

Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom - diabetes

Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom - stroke

Socialstyrelsen (2011): Somatisk vård och sjuklighet vid samtidig psykisk sjukdom – cancer

<http://www.socialstyrelsen.se/publikationer2011/2011-6-15>

¹³ Försäkringsavtalslag (2005:104) https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/forsakringsavtalslag-2005104_sfs-2005-104

¹⁴ Diskrimineringslag (2008:567) https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/diskrimineringslag-2008567_sfs-2008-567

¹⁵ Diskrimineringsombudsmannen: <http://www.do.se/lag-och-ratt/diskrimineringsarenden/if-skadeforsakring-ab/>

growing problem, since the impact of the public insurance is decreasing.

4. 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.

According to the Patient Act¹⁶ information about and the possibility to take an active part in decisions regarding one's health care should be provided. However, the law is not a patient rights law, and patients are left to the goodwill of the County Councils and health care providers. This is especially severe when it comes to mental health care. In Sweden, for example, a health care provider can give non-reversible treatment such as electroconvulsive therapy without consent.

There is very little data on access to sexual and reproductive health care for women and girls with disabilities. Our comments are therefore mainly based on experience from our member organisations. When it comes to sexual and reproductive health, very few County Councils – if any – give technical aides needed to be able to have sex. There are no regulations on what an assistant can or should help with¹⁷. There is also very little information for persons with intellectual disabilities on sexual and reproductive rights. Many of our members have had problems when giving birth due to lack of knowledge concerning their disability or chronic disease.¹⁸ If a person with an intellectual disability is having a child, there are no rules or regulations on what kind of support they should get to be able to fulfil their role as parents. In some municipalities no support is given, in others the child is immediately taken away from them. Hopefully we will have more information in June 2019 when The Public Health Agency of Sweden (Folkhälsomyndigheten) will present a report on sexual and reproductive health for persons with intellectual disabilities.

¹⁶ The Patient Act/Patientlag (2014:821): <https://lagen.nu/2014:821>

¹⁷ Don Kulick, Jens Rydström (2015), Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement. In this book the authors compare the situation in Sweden and Denmark, and the result is that these two countries deal with these questions in very different ways.

¹⁸ Handikappförbunden (2016), Förlossningsvård och kvinnors hälsa <http://funktionsratt.se/wp-content/uploads/2017/10/F%C3%B6rlossning-och-funktionsneds%C3%A4ttning-inspel-fr%C3%A5n-Handikapp%C3%B6rbunden-2016.pdf> (Handikappförbunden=Funktionsrätt Sverige)

5. 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.

On a national level we are regularly invited to have our say on official reports of the Swedish Government (SOU). We are also consulted by several public authorities. However, with some public authorities we are not involved at all. That is the case with for example The Public Health Agency of Sweden (Folkhälsomyndigheten). Others have just started to look at how we could be involved in their work.

At the County Council level, where the health care is provided, there are immense regional differences. In some County Councils the patient- and disability rights organisations are deeply involved in planning and decision making. They receive sufficient information before the meetings, economic compensation for the time to prepare before and to attend the meetings, and they are also given basic funding for their organisations. In other County Councils the patient- and disability right organisations get no or low funding and are therefore not able to be a strong advocate for disability rights.