The rights of older persons with disabilities in Sweden

Although Sweden enjoys very high respect in the international community regarding its human rights record, the legal situation for older persons with disabilities remains weak.

In Sweden there are mainly two laws that regulate the right to help for older people with disabilities:

1. Socialtjänstlagen (SoL) - Social Services Act

2. Lagen om stöd och service till vissa funktionshindrade (LSS) - the Act regulating
Support and Service to Persons with Certain Functional Disabilities

The first law should entitle persons independent living with “fair” living conditions and the second law should entitle persons “good” living conditions. In both cases all help/aid should be given with “good quality”.

LSS contains ten “rights” that can be obtained by a person with disabilities given that certain criteria are met. Personal assistance is one of these rights.

In order to get personal assistance however the person has to have acquired the disability before the age of 65 years.

This means that the Swedish legislation governing the rights for people with disabilities is discriminatory towards older persons, unless they have had their disability already before they became 65 years old.

Someone who gets paralyzed or suffers from a brain trauma at the age of 66 years can therefore not get a personal assistant as helper, but has to rely on the general helpers from the local municipality where the person is living - according to the SoL legislation, and has to be content with “fair” living conditions.

Now SoL law clearly stipulates that all aid/help should have good quality. The legal and political practice however is that an older person with disabilities has to be content with fair quality and not good quality.

**No quality control**

How come? Well, the Swedish administrative courts do not try if help given meet the minimum requirements stipulated in the Social Services Act (SoL).

The SoL law states that all service provided within the framework of the law should have “good quality” but that it should insure “fair living conditions”.

From the very beginning however when the legislation entered into force in 1982 the policy has been to put an equality sign between the level of living conditions and the level of quality the service should have.

This means that a service which aims to “fair” living conditions only has to have fair quality, even though it is stipulated in the law that it should have good quality. This has a severe impact on the level of service that is given to older people with disabilities.

The legal control when it comes to older people with disabilities is limited to whether a person is given the help needed on a very crude materialistic level (does the person need help with hygiene? does the person need help getting dressed? etc), not if the help actually helps the person to live an independent life and if the help is of good quality.

Persons who have obtained their disabilities before the age of 65 however are assured that their help is given with good quality and that it leads to an independent living.

**Checks and balance**

The idea in Sweden is that the administrative courts should not control how aid/help to persons with disabilities is given, when it comes to older people. This task should be carried out by The Health and Social Care Inspectorate (Inspektionen för vård och omsorg, IVO)

IVO is the government agency responsible for supervising elderly care, healthcare and social care, and activities in accordance with LSS.

IVO however focuses completely on structural issues; Is there a log over social activities? Are the nurses and other parts of the staff certified? etc. The agency does not control at all if the help/aid given to older people with disabilities keeps good quality. The situation of the specific individual is overlooked.

Given this situation, where both IVO and the administrative courts ignore quality issues, older people with disabilities are without legal means to demand that help keeps the level of quality which the law actually stipulates.

The way that the inspections are carried out, with focus on structural issues rather than the situation of a specific individual, also leads to that there is a severe lack of accountability in the Swedish system. It is extremely seldom that any single individual is held responsible for abuse against an older person with disabilities, even when one or more individuals can be singled out as responsable.

**Age discrimination**

This difference in how people with disabilities are treated depending on their age is a crucial dividing line in Swedish disability policy making and disability services.

If you have problems in your livelihood due to disabilities in Sweden and need help, you should contact your local municipality. It has the legal and political responsibility for the people living in a town.

When you call the helpline of for example the capital Stockholm, or any other municipality for that matter, and ask for a contact to get help due to a disability, the first thing they will ask you is “how old is the person in question?”.

If you, or the person who you are calling on behalf of, is older than 65 years you are referred to the department for elderly care. If the person is younger, you are referred to the department for disability aid.

This way, older persons with disabilities are not even considered having a disability. They are just old.

This way, the legislation and the political policy making in combination, maintains a very strict line between disabled persons and older people.

This practice is also maintained and reinforced by the NGOs working for older people or people with disabilities. None of the NGOs that work with issues regarding older people actively works with disability issues, and none of the NGOs that work with disability issues has an active policy when it comes to helping older people (+65) with disabilities.

All in all, the question of rights for older people with disabilities in Sweden is practically completely absent or dead.

And, this all comes down to the legislation in force and the age limit for personal assistance to people with disabilities.

Sweden has ratified the UN Convention on the Rights of Persons with Disabilities and it has a special legislation that should implement these rights. However, these rights are legally and practically limited to people who are younger than 65 years old.

Older people with disabilities are legally and practically discriminated in Sweden, and this is done consciously.

In the light of the above it is clear that Sweden does not meet the rights stipulated in the UN conventions on human rights.

Kind regards

Lars Björk

Don't older people have human rights?

*Older people with need of assistance are systematically deprived of their human and civil rights in Sweden. Lars Björk describes a system where caretakers almost completely lack legal rights, relatives are forced to carry out unpaid work, and toothless supervision mainly confirms the misery.*

### **Sweden has a good reputation with regard to human rights, both at home and internationally.** **However, a group that is often ignored is older people with disabilities.** **Their rights are violated almost daily.**

An elderly person with disabilities who cannot defend himself physically or

verbally risks being exposed to a number of limitations when it comes to rights that are taken for granted by almost everyone else in Sweden.

It can be about "small things" like not having your nails or hair taken care of and cut, not getting proper dental care and thereby, in the long run, lose teeth and the ability to eat

ordinary food.

It may be about not being allowed to go to the toilet and instead having to use incontinence protection (diaper) as toilet, to be forced to sit in used diapers or face people (staff) who cannot communicate in the person’s own language or who are even directly unpleasant or verbally abusive. These older people often face having their mobility dependent on

others, and thus severely restricted.

All this occurs in Swedish elderly care, every day, regardless of whether it is conducted in

public or private management. And quite little is done to address these problems.

One basic problem is a system error. Older, disabled persons are deprived of some basic legal rights, and the group as a whole suffers from a serious shortage of influence over their everyday life in the current system.

The Health and Social Care Inspectorate (Inspektionen för vård och omsorg, IVO) is the authority that should protect elderly in need of assistance, against abuse by the state, in reality the municipality where the elder person is living, and abuse from staff responsible for carrying out the required assistance.

IVO should also ensure equal, high quality care.

But IVO's supervision is inadequate. All of its investigations are based on the assumption that what the municipality's employees say in an investigation is true. No real attempts are made to examine what might have been done wrong. "We're not a court or the police," an IVO investigator told me.

**Documented abuse ignored**

Not even when documentation of abuse and violations exist, such as photos, sound recordings or video recordings, the municipality or staff are obliged or required to answer. Words still stand against words, it is said, and complaints from older people or their representatives very rarely lead to any criticism, and even less any actions. Usually complaints are just written off.

The police also seem to take after the attitude of IVO when it comes to older people with disabilities. One suspected abuse of staff against a caretaker does not necessarily even lead to a preliminary investigation, even less to prosecution, despite good evidence. This is often because intent is said to be missing.

Or as in my mother's case, where there were gross handling errors in the investigation, where the police claimed before the prosecutor that there was no crime scene, even though this was clearly stated in the filed complaint to the police.

"Why would the staff abuse your mother?" the prosecutor said, after shutting down

the preliminary investigation regarding the abuse of my mother. I had made a police report after I discovered that my mother had large and recurrent wounds on one of her forearms, and that her bathroom walls were sprinkled with blood.

Yes, why would the staff abuse my mother? Because they think she's difficult, maybe?

Because they had had a bad day, or other problems that could trigger a violent behavior? Is the question asked when it comes to suspected abuse of a young, healthy person?

The basic attitude of the authorities seems to be that personnel responsible for the care of the older people with disabilities never make mistakes or commit crimes. In my mother's case, no interrogations were even conducted with the suspected perpetrators.

**Lack of accountability**

The possibility for older people with disabilities and / or their relatives to demand accountability for abuse against older persons is simply severely limited.

If something happens, it’s considered an accident, or it’s said to be the fault of the caretaker - things that simply happen to old and old frivolous persons. Of course, caregivers often have a heavy and stressful job, but this should not lead to a de facto situation of lawlessness for those they help. Would we accept a similar situation for any other group in society?

Someone has called this attitude "the benevolent dictatorship". It is assumed that when it comes to the care of older people with disabilities there is a constant benevolent will from society, and although this will can be very strained, its presence covers up all possible forms of abuse.

Most people know that the care of older people with disabilities is not always good, but the collective image in Sweden however is that it is generally good and that the neglect, the abuse and the violations against older people that occur are seen as occasional and individual cases and not the consequence of structural problems.

But without a system of accountability in these individual cases, what prevents them from being the rule, the effect of systematic errors, rather than the exception? Remarkably enough, IVO, the authority that is supposed to protect the rights of older people with disabilities, has arrived to this conclusion: Older people with disabilities that need assistance, and their relatives, are in reality “without legal rights” when it regards how granted assistance is carried out since there is no way for those individuals to make a legal complaint in this regard. More about this later on when we get to the authority's (lack of) responsibilities.

**Lack of coordination**

Another system error is a constant lack of coordination and a holistic view of the health care and caring for old persons with disabilities. Simply put, a lack of accountability.

Children of older people with disabilities, or the spouse, draw a heavy load in the Swedish system. Much of their unpaid work consists of administering and coordinating the help that their older relatives receive from the municipalities and the regional health care, since a coordinative function is missing in the system.

This is despite the fact that the Social Services Act, Chapter 2. Section 7 stipulates that municipalities and regional health care councils shall cooperate when it comes to health care.

The institutions must, according to law, establish an individual plan, also called "coordinated individual plan", or CIP, to organize this cooperation for each individual with multiple health issues. Individuals may also request that a CIP be established, by applying to the local health authorities.

**Self-governance**

This all sounds very good. The catch, however, is that the plan will not be drawn up unless the municipality or regional health council considers it necessary. The individual can thus demand that a CIP be established, but the municipality and / or county council may choose to ignore the request. Municipal self-government simply overrides individual rights. The law is completely toothless.

And this is the essence of Swedish policy and legislation when it comes to human rights for older people with disabilities: Their rights are always overruled by municipal self-governance. The rights of political institutions are much stronger than than the rights of individuals.

The system also puts the relatives in a difficult position . According to Swedish law all care and health care that relatives perform should be voluntary, but in reality it is not so since the system forces relatives to take responsibility for their next of kin.

When the coordination between the municipality and county councils fails and the efforts in elderly care do not have good quality, the relatives of the elderly are forced to interfere. And this happens systematically.

About 140,000 adults have been forced to fully or in part stop working to support one

relative, with reduced or no income as a result. This was shown in a study by the researcher Petra Ulmanen presented in 2014. Amongst the relatives who are middle-aged, just over 40 percent provide unpaid family care at least once a month.

However, the elderly themselves prefer that help should come from elderly care, especially when it comes to intimate hygiene, in order to be able to have a normal relationship with their partner or their children.

*April 25, 2018: Tomorrow it goes off again, to Mordor (aka Karlstad) to help mom.* *When*

*the state (read the municipality) does not take its basic responsibility relatives are forced to intervene. Usually I go to Värmland (the country where Karlstad is located) every four weeks to give my mother some social presence, to help her get out and have a coffee, and to cut her nails or to get her hair cut.* *This time I will go with her to the dentist.*

My mother has extensive functional impairments after a severe brain haemorrhage and

needs assistance to take her medicine, rehab and care - thus efforts from both county council and municipality. Like many other older persons with disabilities, and their relatives, this has worked badly, and when I was told about the possibility of applying for a CIP I did it.

I didn’t go very well.

**State of law?**

My mother's hometown, Karlstad, did not even treat the application that we sent in. It was filed without action - so there is not even a government decision that we could appeal.

Ignoring an application this way is quite obviously a violation of both administrative rules and the section about CIP in the Social Services Act. The municipality does not care when this is mentioned, and other sanctions do not seem to exist: the police did not even investigate a complaint presented to them about misconduct.

Is this a reasonable conduct in a state with rule of law? Or vice versa; is it reasonable to call a state that works like this a state governed by the rule of law?

*“Her scream is loud and strong of pain and despair, She is in pain.* *It hurts my soul*

*to hear her.* *The scream cannot be misunderstood.* *Mom is hanging in a kind of lift*

*used to force her up in an upright position, against her will.* *It hurts.* *Mom has pain from the treatment.* *However, the staff standing next to her ignores the screams and continues with what they are doing, as if nothing has happened.* *"We will soon be ready," they said.* *As if the pain was something that mom just had to endure. ”*

This happened when I was visiting my mother at the elderly home where she lives in Karlstad. It was an autumn evening in 2015 and I had just intended to drop by for a moment to say good night. Personally, I didn't sleep at all that night.

**Lack of quality control**

IVO is a remarkable authority. Maybe we can call it the spider in a faulty system network.

Quality deficiencies in health care are not really examined by IVO, despite demands that all help to older people with disabilities should be of “good quality”, and that the authorities should carry out systematic quality work.

The administrative courts do not examine quality deficiencies either, which means that the older caretakers with disabilities in reality lack legal protection when it comes to quality control. IVO itself, strangely enough, arrived at the same conclusion in a report from 2014:

"There is normally no possibility for the elderly to get the assistance that they receive

reviewed by a court," IVO wrote in its report. Despite this finding, the authority presented no proposals to the government on how this situation should be handled/improved.

The municipalities however were asked to review their work code. Such a review is completely voluntary and without any threats of sanctions, of course. Self-government of the municipalities in Sweden simply overrides human rights of older people with disabilities.

To be able to make a legal complaint of the decision making of authorities, to be able to appeal authority decisions, is one of the basic principles of the rule of law. The fact that this is not always possible in Sweden is in direct conflict with the UN Convention on the Rights of Persons with Disabilities. It also violates the European Convention on Human Rights, which applies as law in Swedish.

**Elderly ignored**

Despite these blatant system errors, which violate Swedish law, the issue shines with its absence at all parliamentary parties, and unfortunately also at most disability organizations and elderly organizations in the country.

When the Government launched an investigation in 2016 to examine the Swedish elderly care and present a national quality plan for this field, the rights perspective was completely absent. It was simply not part of the mission statement from the government. Despite this both the government and its investigator Susanne Rolfner Suvanto declared that "Swedish elderly care is the best in the world".

With that attitude from the highest power, perhaps it is not so strange that the supervisory authority IVO is so weak. It makes no direct demands to the municipalities to review system errors or to even carry out systematic quality work. Despite that the National Board of Health and Welfare have demanded precisely that.

If we are to compare the situation with another group in need of care, children, the Swedish Schools Inspectorate is far more active in its supervision.

Of course, this does not mean that children with disabilities are not discriminated against, they are, but problems concerning children are noticed in a completely different way. There is even a special NGO that works specifically with issues related to children with disabilities -

RBU. Nothing similar exists when it comes to older people with disabilities. Nor do the pensioners’ organizations focus on the problems of older people with disabilities.

**Freedoms violated**

The current situation implies that we all should consider how human rights actually work in Sweden. Do they only apply to the strong and capable? For certain, the protection is strong for the individual - if the individual lacks a need of assistance from society.

If you do not need help, you are protected from someone entering your home against your will. It is otherwise called trespassing, and the police and prosecutors will come to your assistance! If you are not in need of assistance, you are in the same way protected against someone touching you against your will. Otherwise called molestation.

You are also protected against someone trying to force you to go to bed when you do not want to, to prevent you from taking a shower or go to the toilet whenever you want. Such actions would be assault, unlawful coercion or detention. Severe crimes.

You also have the right to move freely as citizen in Sweden, meet who you want, whenever you want, as often as you like - if you do not need assistance. You have the right to read the books and newspapers you want, and listen to the music you want. You have the right to travel wherever you want, whenever you want.

Your rights and freedoms are not limited by the state, but protected by it.

If, on the other hand, you need assistance, especially if you are old and with multiple disabilities, you can forget all the rights listed above.

As an older person with disabilities you do not have the right to decide who will help you

or when it should be done, or for that matter how. This applies to everything from whether or when your nails should be cut, how often you get to the toilet (if someone does not choose for you that you should diapers instead), how often you are allowed to get out, or when and if and how often you get to visit friends and relatives.

**Lack of influence**

In 1996, then Social Minister Margot Wallström (now Minister of Foreign Affairs) presented an amendment to the Social Services Act, which promised "real influence over how the help should be given" to the old persons in need of assistance. Just over 20 years later, older people with disabilities still have no power over how the assistance they are to receive will be carried out .

To lack influence over their care leads to poor quality, the National Board of Health and Welfare has declared. This applies primarily to older people with disabilities.

The elderly who need the assistance from the society in order to survive are referred to the support that their hometown (municipality) wants to "offer", as if it were a favor, and not rights. The reminiscent of the past times poor relief.

The will of the state to simplify and improve matters for this large and vulnerable group shines with its absence. For example, did you know that if you have a travel service certificate, it only applies within you own municipality, or the county. For longer trips, you must apply for a national travelling approval. For every single trip that you want to make. And you have to apply for this several weeks ahead, for each trip.

Or take the dental care, of course fundamental to the older persons with disabilities, the well-being and the quality of life of the sick.

Unfortunately however, my mother's home municipality does not take responsibility for her dental care. So I, as a relative, get have to arrange for this, despite that I live 300 km away, or accept that her teeth rot and fall out.

And the relatives who are forced to arrange the dental care? Oh, yes, according to the law, they do this "voluntarily".

*March 9, 2017: The day after International Women's Day.* *Swedish elderly care in Karlstad.*

*Mom loses a button in her sweater.* *No one sews it back.* *No one moves the top button so that the sweater can be closed in the neck.* *The open sweater makes mom cold.* *Nobody does anything.* *"We do not sew buttons" the staff tells me. Well. Who will do it then?*

**Situation ignored**

To my despair there is almost a compact silence about the situation of older people with disabilities. No one seems to care. For the last five years I have tried to raise the issue of discrimination against older people with disabilities, in different contexts. I have traveled to the annual Swedish political event in Almedalen, met representatives of the large

pensioners' organizations, and had meetings with several members of the Swedish parliament’s Committee on Social Affairs.

Everyone has been empathetic, and seemed to have understood that today's systems have serious legal shortcomings regarding older people with disabilities, and they have all acknowledged that their human rights are violated, but no one, not a single person, has been interested in doing anything about it - regardless of political colour and platform.

No one has wanted to raise the issue in the parliament’s committee on social affairs, or in an interpellation to the responsible ministers. Nor has has any debate articles been written on the subject. Promises have been made to “look at the question”, but when I have later reminded of these promises, I have only been met with irritation.

I believe that the legal situation is so deficient for seniors with disabilities, due to a basic contempt for weakness and old age. In 1997, Lars Andersson, professor emeritus in gerontology at Linköping University, baptized this discrimination “ageism”.

The treatment of the old people with disabilities is a major challenge to the status of the human rights in Sweden. Should these rights be taken seriously, they should apply to everyone, always. I hope to see the strong HR-organizations that exist in this country, discover this, and take the fight.

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