

8th of March, 2011

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Dear Members of the Committee, and of the Secretariat

Most persons with complex psychical disabilities in Sweden have good reasons to appreciate the kind and efficient solidarity, shown by Society. But not all.

The Swedish Society is **not respecting all rights** and is **not practicing** what is stated in the *UN Convention on the Rights of Persons with Disabilities*, articles 19, 24, 12. Our Society refuses or neglects to *adopt all appropriate legislative measures for the implementation of the rights recognized in these mentioned articles of the present Convention*, as stated in article 4.

With this letter we wish to present and submit facts and experiences that show **an obvious imperfection** in the Swedish way of *undertaking to ensure and promote the full realization of all human rights and fundamental freedoms for persons with disabilities*.

If and when the mentioned articles are included and implemented in Swedish law, significant improvements will immediately be made available to all psychically disabled persons.

<u>Table of Content</u>	<u>Page</u>
1. Introduction. Who we are, and why we are writing to you.	2
2. Our hopes and expectations	3
3. Sweden has ratified the Convention but still does <b>not respect and practice</b> articles 4, 12, 19, 24	3
. Swedish Courts contradict and do not accept and apply what is stated in <b>Article 19</b> . The rights expressed in this article are denied, and not practiced by Social Authorities	4
. Ambitions expressed in <b>Article 24</b> cannot be met if article 19 is not observed, granted	4
. <b>Article 12</b> is not observed, not practiced, although its rights are required to accomplish a thorough and justified appeal to the Courts, when Article 19 is denied	4
. Statements made in the Convention, articles 12, 19, 24, are not adopted by Swedish law, although such measures are said to be compulsory in <b>Article 4</b>	4
4. A significant number of psychically disabled persons are <b>denied</b> these rights	5
5. Experiences show that psychically disabled persons being allowed to choose care-provider get <b>more promising results</b> from social care	
6. <b>Why</b> Swedish Courts and Social Authorities <b>neglect</b> these rights	6
7. The new Law intended to offer <b>freedom of choice</b> has no effect	6
8. Statements concerning Social Care made by the <b>Minister for Children and the Elderly</b> , and how these are interpreted by persons with complex psychical disabilities	7
9. Plead for UN Committee attention and action	9

## The report

### 1. Introduction. Who we are, and why we are writing to you

We, parents and relatives of persons with complicated psychical disabilities that - according to Swedish law (LSS) - are entitled to special attention and care by Society, are writing to you, the Committee and the Secretariat for the Convention,

- First to **express our gratitude** for the fact that this Convention has been worked out, in order to be applied as policy and legal direction, and to be implemented in relevant formal and practical procedures to be used when assisting disabled persons, and aimed at guiding Society on how to grant the rights and meet the needs and hopes from disabled persons in practical life.

We are grateful for the solidarity shown disabled persons by modern Society. And we appreciate that Sweden, our domicile, has recognized, ratified and agreed to what is suggested and set out in this Convention, with the acknowledged ambition to implement its intentions and its legally valid and binding conditions, and assist and support disabled persons accordingly.

- and Second to report back - based on experiences made by **some suffering disabled**, and relating that to what has been stated - on how the Convention is being applied in our country, where **some important Articles are not being fully observed**, not being implemented in accordance with what is prescribed, with what has been agreed.

We believe it makes sense that the Committee and the Secretariat will get not only **official reports** from State Authorities, but also **feedback from those concerned** by efforts made, the disabled. Obviously the two kinds of reports will show significant differences.

## 2. Our hopes and expectations

We hope that you will see that what has been stated in the Convention, its **article 19**, is directly **contradicted** and not respected by what the Swedish Supreme Administrative Court has prejudiced on that same issue.

We hope that you will find it appropriate and motivated to remind the Swedish Ministry of Health and Social Affairs that **all** Articles in the Convention **must be observed and respected**, including what is stated in **articles 4, 12, 19, 24**, thereby allowing this report from persons with complex psychical disabilities to be taken seriously and be received as a friendly **appeal to take action**.

In the Introduction chapter of the Convention it is explained *why* the Convention is needed: It is intended "*for persons with disabilities that are being **denied human rights**. The Convention sets out the **legal obligations** on States to promote and protect the rights of persons with disabilities. The Convention is **legally binding**".*

These motives and imperatives are very clear. As disabled persons that we here refer to are **being denied significant parts of their human rights**, we believe it to be appropriate and in due order to write this letter and **report to the Committee and to the Secretariat**, thereby trying to get attention to the insufficient and inadequate implementation of critical parts of the Convention in our country.

## 3. Sweden has ratified the Convention, but does not respect and practice all Articles. This creates serious problems for some disabled.

Sweden has ratified the Convention , and has hereby agreed *to take all appropriate measures, including legislation, to modify existing laws, regulations, customs and practices*. Such undertaking should of course include also what is stated in **Articles 4, 12, 19, 24**. This has not been done. (See statements made by the Minister, page 7)

Lack of legislation related to these articles create problems for some disabled

- Persons with complex psychical disabilities need an **active individual pedagogical support** and assistance to live an orderly life and to be able to reach life qualities that are stated in the Convention Article 24, that includes desired goals and ambitions for social care

- Consulted medical and social **expertise** often recommend them to apply for such accurate assistance and support offered by private care providers, who practice an **alternative and more complete pedagogical care** that can be more efficient than others and show promising results for persons with these kinds of disabilities.



- Convention article 19 assigns **the right for the disabled to choose where and with whom they want to live**. With reference to this article, all disabled should be able to choose and join care-providers that offer the most appropriate care, precise and suitable for their needs.



- The Supreme Administrative Court has stated and **prejudiced** (RÅ 2007 ref 62) that *Swedish Law does not explicitly allow disabled the right to choose a preferred care-provider, or to choose where and with whom they want to live.*

Legal source: **RÅ 2007 ref 62**. In Swedish: *Någon rätt för den enskilde att kräva ett visst utpekat boende följer inte av LSS*. In English: ***The right for a person to demand a preferred residence does not ensue from/does not follow from what's stated in LSS, Law concerning support and service to certain disabled***

Community lawyers of the **City of Stockholm** have distributed a regulatory paper which says: *Disabled have - according to a Statement by the Supreme Court – 'no right to choose where or with whom they want to live'.*

**This restriction or limitation of choice is not included in the legal text**, in a law that talks about **the rights** of the disabled, which may be a reason for the Supreme Court to offer their "interpretation". Human rights that are not explicitly stated, are *no human rights*. This is why the **Convention article 19 has to be adopted into Swedish law**, if UN insists upon stating that **choosing where and with whom to live is a human right**

- When considering applications from disabled, that include expressed preferences on *where and with whom to live*, the Home Community refer to the prejudiced statement from Court, and **denies the disabled the right** to get the kind of preferred care that was chosen after recommendations made by medical and social expertise. Such professional arguments are not allowed to have any influence on the formal Social decisions taken.



The Community argument: **You have no right to choose**. *The Community offers an equivalent and purposeful care, comparable with the private care provider. Your application is turned down. We offer you a home in our care, which has proven to be suitable for most disabled. You have, however, the right to appeal at Court, if you are not happy with our decision.*

- The disabled, having been denied the preferred and needed way of living, are entitled to appeal at Court, but is **denied legal advice and legal assistance**. The Convention article 12 says that *State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life*. And, *State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*



In Court negotiations the Home Community is represented by the Community Lawyer, and often by a legal advisor in the particular jurisdictional area. The disabled is **denied such access to legal support** required to argue and cover all legal aspects, and respond to questions that may be of conclusive interest to the Court. **No equal rights.**



- Statements made in the Convention, **articles 12, 19, 24, are not adopted by Swedish Law**, although such measures are said to be compulsory in the Convention article 4

**Article 19** says that *State Parties shall ensure that persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in any particular living arrangement*

This article has two important meanings for the disabled: 1) It is a statement that attributes a civil and human right to choose. 2) It is also a statement that allows a disabled to choose where and with whom to live, based on an understanding of where and by whom the most accurate care and assistance are offered that challenge the individual disabilities. This makes Article 19 crucial and particularly fundamental for persons with complex and psychical disabilities.

Reality shows an obvious lack of consistency and agreement between what is stated in the Convention and what Sweden - as a ratifying state - has decided to "commit to" and implement.

4. A significant number of disabled persons are denied these rights

We estimate that **some 100 psychically disabled persons per year** are "forced into conflicts" with the Swedish Society concerning *where and with whom they shall live*, or rather with whom they *should be allowed to live*, but are denied that right.

This may seem a small number, in percentage of all disabled. It is a small number of the total population. But the Convention underlines that **human rights should be granted every individual**.

When persons with complex psychical disabilities apply for the right to live with a certain preferred care-provider, the hope is to get the most efficient assistance in finding life conditions that will facilitate all daily routines, self control, social life with others, work that engages all kinds of the individual capacity, and an order of life that may develop previously unknown potential strengths.

Of those disabled that are denied a preferred care provider, many will **appeal at Court**. And again be denied the right to choose. Almost all will therefore - against their will, and against clear recommendations from medical and social expertise - **be forced to accept Community Care** (that may be efficient for some, but not for all), forced to accept a kind of assistance that will **not show desired and potential results**, not develop capacities, and turn out to be a severe limitation for these disabled, as a formal way of just being looked after by Society.

5. Experiences show that psychically disabled persons being allowed to choose care-provider get more promising results from social care



Disabled persons that succeed to get assignment with care-providers of preference and choice, reach **results that often show to be far beyond expectations**. Moving from a traditional Community Care to a private care with the alternative pedagogic work pattern has in several cases shown that difficulties that derive from disabilities turn to be less obstructive.

Persons previously unable to speak have started to speak after a short time. Persons previously heavily dependent of medical treatment to be able to calm down, concentrate, have become less dependent of

expensive medicine, and more in control. This kind of progress has in turn opened opportunities for disabled to actively participate in social life with others, and to participate and make valuable contribution in daily work.

These kinds of results **should encourage** Society and Authorities to appreciate and to learn why and how it is possible for psychically disabled to make real progress, and that **the right to choose the accurate care-provider** and a preferred life style support makes a difference.

#### 6. Why Swedish Courts and Social Authorities neglect these rights

We believe there are two reasons for the Court System and the Social Authorities to deny disabled the opportunity to *choose where and with whom to live*, or which care-provider to prefer and apply for.

- The **Swedish Law does not explicitly express the right to choose.**

This may be so. But Courts have taken the position that a small mistake or lack of clarity by the previous legislator when materializing and verbalizing the present law **should be understood as a restriction.**

We have consulted with those politicians and their expertise, that originated this particular legal act, and now know that they had no intention to restrict opportunities for disabled the way this is done in today's practice.

- Community officials often refer to private care-provider's **pedagogical efforts to be more costly.**

We have found that costs for care programs, measured as costs per comparable care activity, normally coincide between different providers. Some private care providers have however invested in activities that lead to improved results, allowing disabled to decrease the use of medicines, to reach higher levels of self control and thereby to decrease the dependence of assistance from others. To reach these improved levels may of course initially cost some more than continuous support without further progress for the disabled.

One has to consider **cost-benefits, not only costs** in Social Care, and when supporting disabled.

#### 7. The new Swedish law intended to offer *freedom of choice* (LOV) has no effect

Two years ago a new legislation was introduced, LOV (Law offering *freedom of choice*), promoting **the right to choose for people with need for Social Care**. The introduction of this law was restricted in a number of ways, which has meant that psychically disabled have **not been offered a true choice**

- Every Home Community has a right to decide **whether or not to implement** and apply the law. And whether or not it should be offered for non-disabled elderly only, or whether alternative choices should include only care-providers within the Community, and Community Care providers only
- Communities that implement the new law, are expected to list care-providers which the Community has selected and acknowledged, that have agreed to sign letters of understanding. Such agreements can be signed only when care-providers show conditions for care that are transparent with conditions shown by all other types of care-providers. Support activities and contributions from care-providers with intentions to assist persons with special needs may have to be abandoned, or financed by other sources, **if and when these care-providers want to qualify** for Community approvals.

The new law, LOV, does not meet the requirements of the Convention.

8. Statements concerning Social Care made by the *Ministry of Social Affairs* and by the *Minister for Children and the Elderly*, being responsible for these issues

- In a political report, 2005. The *Minister for Children and for the Elderly* is a member of Government. She was in 2005 chair person of a broad political but nongovernmental Committee which, one year before the public elections 2006, expressed the ambition to revise and **adjust the law and the applied procedures** intended to assist persons with psychical disabilities.



It argued: *Persons with disabilities must have the right to decide on their own life. Let's introduce **free choice of residence for persons with disabilities**. Today's Social practice is aimed at satisfying demands of the Communities, and limit support programs for disabled to include only a minimum of care. It does not satisfy demands of the disabled. Selecting a care provider seems to be restricted to what can be offered by the Community "imprisonment of disabled" does exist.* (Our translation)

- In a Government report, 2006. After the election, after having moved into office, when announcing a Social program, Government declared: *Possibilities for disabled persons **shall increase**.*

Our view: Government decided to **give up its original position**, with a firm promotion of **free choice**, in favor of **free choice when possible**. Common praxis has shown that this latter statement has had no impact on Society procedures when assisting disabled.

- In an official statement in media regarding the Elderly, the Minister declared: *Government will promote the right for Elderly with a need for Social care to have the right to **choose residence**, where and with whom they want to live.*

When questioned by the Political Opposition, the Minister argues: *Why shouldn't Elderly have **the same right as all of us**? I can't see any good reason why we should allow bureaucrats in Home Communities to determine the lives of the Elderly, and determine where and with whom they should live?*

Our view: A similar position statement should have been made also for persons with psychical disabilities. We suggest: *"Our understanding is of course that we should **allow disabled the same right** to choose residence, including the right to choose care providers that can offer them the most relevant and - with due respect for their disabilities - the most accurate support and assistance"*

- In a letter from the Minister to us in February 2011, as a response to our letter sent to the Minister in August 2010, with questions on why Society is neglecting fundamental human rights for psychically disabled persons, e g denying *the right to choose where and with whom to live*, thereby **disregarding statements** made in Articles of the *UN convention on the rights for persons with disabilities*. We concentrated our questions to **Articles 4, 12, 19, 24**.

The Minister answered (the following quotes are **extracted** from a 3-page letter, and **translated** to English by us, to the best of our knowledge)

- . The Minister: *"I underline the importance of creating a political direction that allows the **UN Convention to have a significant effect** on Society. I want to mention that Sweden **fulfills and carries out those demands** of the Convention, that are to be*

*understood as “absolute”, unconditional, where the Convention demands or commands that disabled without exceptions **shall have the same rights granted**, or guaranteed in law. This goes for Articles 10-14, 15-17, 23”*

Our view: We believe that also the **articles 19, 24, 12, 4** should be understood as “**absolute, unconditional**” for persons with complex psychical disabilities. It must be acknowledged *as a human right to choose where and with whom one wants to live*, and from which care-provider one prefers to get the necessary care.

- The Minister: “*When answering your questions I want to mention that Sweden has **good chances to fulfill all demands** of the Convention, although there are areas where **work remains to be done** until goals and demands that are stated in law may be viewed as fulfilled. Examples are Articles 8 and 9, and 27”*

Our understanding: We find it surprising and discouraging that the Minister does not see the kinds of difficulties persons with complex psychical disabilities are confronted with when applying for a preferred care-provider. This lack of understanding clearly shows and underlines the need for Sweden to **reconsider its position and fulfill also demands stated in articles 4, 12, 19, 24**.

- The Minister: “*In order for Government’s policy and goals for persons with disabilities to become effective, groups engaged in the matters **must work together** to identify and **remove obstacles** in the labor market for persons with disabilities that restrict their working abilities”*

Our view: We have tried for three years to attract the attention of the Ministry and the Minister to observe the difficulties for psychically disabled, and to allow the choice of a more accurate care. We have encouraged the Minister to carefully study and consider all the yearly Court cases in which disabled - with help from relatives and friends - have **tried to get a fair treatment by Society by appealing to the Court of Law**.

Persons with complicated disabilities that live with care-providers applying alternative pedagogic assistance and support, have shown to have **better working abilities, less obstacles**, and **participate actively** in those parts of the comprehensive and in many ways normal labor markets that are included in these more progressive care-provider programs.

- The Minister: “*To get access to further information on what the Government is doing to reassure that the Convention is being observed, obeyed, I refer to the **Government report to the UN committee** that will be made available on the Government webpage within short”*

Our view: We have studied the report, made official in January this year. The report says the following: *Sweden is obliged and committed to legally do what’s required in the articles. But the Convention **does not per se create any new rights** for disabled.* This is **not true**. The Convention - when implemented correctly - will introduce a **new right for disabled ‘to choose where and with whom to live’**.



- The Minister: “*I value as a Minister to take part in your views on this **important** issue. It is important that Government has an ongoing dialogue with the civilian part of*



*Society, that has a significant meaning for establishing the policy, and an important role as ‘pressure groups’”*

Our understanding: We would welcome a constructive dialogue that includes the **Ministry’s interest in experiences made by disabled persons**, for whom all these efforts are made.

In summary: The Minister did not answer our questions on why the quoted Articles are **not being observed**, not implemented in Swedish law, and in real life of the disabled. These articles, we believe, will only become part of the Social practice in our country, if and when directed efforts are made by the *UN committee on human rights for persons with disabilities*

#### 9. Plead for UN attention and action.

We have learned to appreciate the kindness and solidarity that the Modern Society shows all disabled. The fact that UN has provided a set of rules intended to govern Society’s dealing with disabled persons allows us to believe that the disabled could be even more ensured to get a fair chance to grow and develop in ways that are similar to what non-disabled may experience.

Our hope is that the Committee and the Secretariat, after having considered this report, will **identify appropriate ways and measures to communicate with responsible Authorities** in our country, in order to secure an accurate and comprehensive way of applying the missing Articles, in law and in real life.

Kind regards from

**ILG, Individuellt Liv i Gemenskap** (An Individual Life for disabled, in Community with Others)  
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All signatories have **signed by hand** the document that is being sent by post, and have agreed to show **computer printed signatures** in the document sent simultaneously by email. The **address** to the *Association for Relatives of Persons with Complex Psychical Disabilities* is:

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