



## **Swedish Disability Federation's replies to List of issues**

The Swedish Disability Federation's comments on "the Written replies by the government of Sweden to the list of issues (CRPD/C/SWE/E/Q1) in relation to the initial report of Sweden, adopted by the Committee at its tenth session (2-13 September 2013)".

### **Swedish Disability Federation**

The Swedish Disability Federation is a politically and religiously independent coordinating body for national disability organizations. Our vision is a society for all, where all people can participate on an equal basis, regardless of functional ability. A society that protects human differences and human rights and therefore is a rich society.

The Swedish Disability Federation represents 38 member organizations with 400 000 individual members.

### **Introductory remarks**

In this document, the Swedish Disability Federation comments and complements the Government's response. In conclusion, the Swedish Disability Federation considers that a rich country like Sweden should be doing much more to combat the structural discrimination that people with disabilities often experience.

The Swedish Government's lack of respect for its international agreements is most obvious in relation to question 13, which is scandalous and unworthy a country like Sweden!

(The fact that the government has not responded to several of the Committee's questions shows also the government's lack of respect for their international commitments.)

Before the Convention came into force in Sweden, there was a government bill that marked a clear political will, as reflected in the title: From patient to citizen. The government communication with the disability policy strategy, which is the government's tool to live



up to the Convention, is limited to a number of smaller specific measures and have never been discussed in parliament. Not even these measures are carried through by the government which instead launches new inquiries. In several areas, the living conditions have deteriorated since the Convention entered into force. A few examples:

Many people in recent years have lost their assistance at a reconsideration even though the disability has not changed. New inquiries are launched continuously in this area and persons eligible for assistance have their needs increasingly questioned. Inquiries with proposals for reforms in the area of labor market and social security are available but not realized. A reinforced discrimination law has despite decades of inquiries not been realized.

Lack of interpretation that conforms to the Convention and lack of access to efficient legal remedies permeate the most areas of rights in the Convention. Measures to enable individuals to pursue their cases in an equivalent way as people without disabilities are of central importance so that the Convention will be implemented in a satisfactory manner. See comments to the questions 17 and 20. Likewise, all individuals must have a real opportunity to report perceived discrimination. As noted in question 12 a large number of discrimination agencies have stopped receiving complaints about crime due to lack of resources to pursue more cases.

## **Purpose and general obligations (arts. 1-4)**

### **1.**

The Swedish Disability Federation confirms that education in order to raise awareness about the personal treatment of people with disabilities is under development. Courts and authorities knowledge of CRPD, including the human rights model of disability and the use of interpretation that conforms to the convention is not included in the current education courses. This perspective was not included in the National Courts Administration's assignment. The following



goals were formulated by the National Courts Administration in the mandate from the government in May 2010.

**Sub-goal 1** All staff in the Swedish courts shall by e-learning strengthen their competence in prerequisites and needs of persons with disabilities.

**Sub-goal 2** In current management educations and courses on personal treatment, prerequisites and needs of persons with disabilities must be considered.

The Swedish Disability Federation confirms the government's description of the e-training courses on accessibility and treatment but is very critical that these training courses do not include awareness raising on human rights in relation to people with disabilities. The Swedish Disability Federation would also like to emphasize that the planned training courses do not involve the entire judicial system, as for example prosecution, prison services, members of a jury, law schools etc.

The Swedish Disability Federation, as a national umbrella organization for 37 organizations has not been involved in the development of this training.

Regarding awareness raising initiatives towards other government authorities Handisam offers knowledge support related to accessibility and personal treatment. Awareness raising initiatives about the meaning of interpretation that conforms to the Convention and usefulness of the Convention are not included in Handisam's current assignment.

## **2.**

The Swedish Disability Federation notes that the Government describes the actions already completed. The Swedish Disability Federation would therefore emphasize that those individual actions on dissemination of knowledge are not enough. We need comprehensive, future actions to increase the knowledge of the Convention's existence and meaning.



The Swedish Disability Federation notes that the government describes actions that are already completed. The training courses carried out in connection with the Swedish ratification of the CRPD have been invaluable for the awareness raising of the Convention.

The Swedish Disability Federation receives still requests from municipalities, county councils and organizations who want to learn more about the convention. Due to reduced resources and rejections of project applications to the Swedish Inheritance Fund, it is not possible for the Swedish Disability Federation to provide study courses.

To ensure that all concerned could be able to pursue a rights-based work, should opportunities be given to study in depth. Significant awareness raising activities among both individuals with disabilities as policy makers and officials is crucial for the Convention to have an impact.

### **3.**

The Swedish Disability Federation confirms the Government's response in terms of statistical monitoring of the Convention. Sweden has by these indicators got a completely different knowledge of the situation of people with disabilities. The indicator system is based only on those areas that relate to the Swedish disability policy. The objectives of the strategy are often freestanding from the Convention. This leads to that the interim objectives that have been developed by the different strategic authorities are not harmonized with the descriptions in the Convention. The consequence is that the national strategy on disability policy does not cover all of the Convention's rights-areas. In several cases, relevant indicators are still missing for us to get a comprehensive picture of how Sweden complies with the CRPD. The system of indicators at the municipal level is voluntary based. This complicates the monitoring at the local level.

**There is also a lack of methods for reliable performance indicators.**



Handisam uses a voluntary web panel to ask questions to individuals with disabilities, but the selection and the method do not constitute a representative basis. It is an especially misleading method to measure digital participation as only digital participants can participate in the panel.

The Swedish Disability Federation confirms that we have consultations with Handisam in terms of indicators. The Swedish Disability Federation's application to the Swedish Inheritance Fund for identifying the absence of indicators related to the CRPD, has been rejected. This means that the Swedish Disability Federation's representatives do not have the opportunity to ensure that all areas of rights are included.

#### **4.**

The Swedish Disability Federation notes that the government did not respond to the question. The government describes only actions related to employment.

Whether budget cuts are a result of government policy or a consequence of the international crisis is a question that must be answered by the government.

Concerning for example employment the Swedish Disability Federation notes that the gap between us with disabilities and those without disabilities increases. The trend has been negative for several years, regardless of cyclical divergence.

Statistics Sweden's labor force survey from 2008 shows that the employment rate for people with reduced work capacity was 50.0 percent. According to their survey from 2013, the employment rate dropped to 44 percent. For women, the situation is even worse. Only 39 per cent have a job. The Swedish Disability Federation considers that this is a remarkable figure that is at odds with the government's stated ambition.



The Swedish Disability Federation also notes that the economic situation of people with disabilities is considerably worse than for other people. Handisam's report shows that:

- It is almost ten times more common that people with disabilities perceive their health as poor, 19 percent compared with 2 percent among others.
- 26 percent of people with disabilities have been in a financial crisis. That's twice as many as in the rest of the population.

For additional statistical data, see item 524 and item 83 of the alternative report.

## **5.**

In January 2014, only 13 of 22 strategic authorities which have an established consultation with the disability organizations. There are only two of them that pay some sort of fee and travel expenses for the consultation meetings. This means that the disability movement cannot always appoint the best suited but must appoint representatives who live close to where the consultation takes place.

Some consultations are handled at a relatively low official level within the authority. At best, the disability movement will have a role in the practical design of various services or activities. We mean that consultation should take place with representation from the authorities management to have any effect on a comprehensive and strategic level. Some consultations also tend to be pure information meetings as at present there is no established and implemented recommendation on how consultation should be done, although several authorities have long had an expressed disability political responsibility inscribed in their instructions.

The Swedish Disability Federation conclusion is that the disability movement's representatives are not valued as experts under the same conditions as other experts or consultants who systematically



are engaged in other issues, and that the government is failing in its follow-up to create effective authority consultations.

The disability movement gets an annual government grant and it has not been increased since 2008, while the increase in costs for salaries, administration and others has increased by 2-3 percent annually. This creates an erosion of the state grant which meant a real reduction of about 12-18 per cent since 2008.

The allocation to the collective disability movement is also annually the same amount, which means that more people will share the allocation when new organisations are added.

The Swedish Disability Federation has initiated a discussion with the government of how the interpretation of Article 4:3 should be made. (i.a. the letter to the responsible minister February 7, 2012). We mean that the Convention expresses that States parties should "actively involve and consult with persons with disabilities through the organizations that represent them," stipulates a higher level of ambition for the state than to organize consultations.

We also have in the same letter expressed our concern that an increasing number of government inquiries are set up without explicitly mandating participation of the disability movement in the directives. Likewise, we see a disturbing trend that authorities and government inquiries handpick "experts" or establish "user panels" which does not have a democratic secured representation from the disability movement.

## **6.**

The Swedish Disability Federation confirms the Government's response that the national strategy on disability policy covers all people regardless of race, gender, sexual orientation and so on. Aspects that especially concerns the intersectionality between people with disabilities are not identified in relation to the rights in the Convention.



Handisam's evaluation of disability policies from 2013 shows that the vulnerability of people with disabilities who are born abroad is clear. Ill-health is higher, unemployment higher and the economy worse.

Handisam's evaluation of the national disability policy (2013) shows that it takes on average 86 days longer for a person of foreign origin to get a code of disability than for a Swedish person. Such a code is necessary for the individual to have access to various efforts related to work and employment.

The report also shows that women with disabilities often have worse living conditions than men with disabilities.

The Swedish Disability Federation can unfortunately see that the vast majority of people who engage in disability organizations seem to be born in Sweden. This means that sufficient knowledge of the specific difficulties that people with disabilities who are born in another country is not in the disability movement.

## **7.**

The Swedish Disability Federation has no comments on the Government's response. However, the Swedish Disability Federation can note that the government has not reflected on the involvement of the disability movement at municipal level, this related to the local government autonomy.

The Ministry of Health and Social Affairs which handles CRPD has not invited NGO's to a dialogue regarding the government's response to List of issues. Nor is this practice for other conventions. As for other conventions, however, Government uses to invite to a dialogue before the hearing of the appropriate committee. Whether the disability movement will be invited to a dialogue on the situation in Sweden before the hearing with CRPD Committee remains to be seen.





## **Specific rights**

### **Equality and non-discrimination (art. 5)**

#### **8.**

Item 42 in the alternative reports shows that the Discrimination Act (2008:567) and The Law (1994:1 2019) of the European Convention on Human Rights and Fundamental Freedoms together contain prohibition against discrimination relating to most of the articles in the CRPD. However, article 9 lacks any protection against discrimination. The European Convention's protection is in some respects narrower than the rights in the CRPD, for example in Article 29.

#### **9.**

The Swedish Disability Federation notes that the Government has not responded to the question. The Swedish Disability Federation has pointed out shortcomings in the translation but has not been invited to do a review of the translation.

#### **10.**

The Swedish Disability Federation confirms that reasonable accommodation can be obtained in relation to employment and higher education.

The Swedish Disability Federation is very critical of how the government dealt with the issue of reasonable accommodation in relation to other areas of rights in the Convention.

The Swedish Disability Federation did not have access to the documentation that will be a government bill mars 2014. The Swedish Disability Federation has also not been involved in the work with the mentioned government bill. The Swedish Disability Federation therefore cannot comment on how Government Bill meets the requirements of the Convention on reasonable accommodation.



## 11.

When it comes to discrimination, the Equality Ombudsman (DO) can at no cost pursue cases where individuals feel they have been discriminated against. DO can however only pursue cases handled in the Anti-discrimination Act and the Parental Leave Act, mainly discrimination related to economic, social and cultural rights. Many civil and political rights are written into the European Convention for the Protection of Human rights and Fundamental freedoms. The European Convention has been incorporated into Swedish law and can be invoked in a court of law. DO can, within the framework of a charge revoke the European Convention, but cannot pursue a case that rests only on it.

Another major problem is that the Equality Ombudsman has only limited possibility to pursue cases and therefore have decided to only pursue precedent-setting cases. This means that many people who want to report cases of discrimination cannot be helped by the Equality Ombudsman. In Sweden there are 14 discrimination agencies. These discrimination agencies are independent from the Equality Ombudsman but also works with all grounds of discrimination that are regulated in the Anti-discrimination Act It is one of the requirements for the government grant that discrimination agencies receive from Swedish National Board for Youth Affairs.

Discrimination agencies give free consultations. Some agencies have also begun to pursue cases to court. At present it is often a matter of minor cases. The agencies have very limited resources, which is also a reason that more cases are not pursued in a judicial process.

## 12.

The Swedish Disability Federation has no comments on the Government's response, but considers that it is important that information on the cases pursued by the discrimination agencies also obtained and presented.

The Network Swedish non-discrimination agencies, SADB can conclude that the number of reports has increased during 2013. The



number of cases related to discrimination on the basis of disabilities is not, to date, compiled. SADB states that several of the non-discrimination agencies have put a stop to reports since summer 2013. This is due to lack of resources to take in more cases.

The latter is something that is confirmed by the Swedish Disability Federation. Several of our member organisations have experienced that their members have resigned. A growing number of people feels that they cannot get help to pursue cases that relate to perceived discrimination.

### **13.**

The Swedish Disability Federation notes that the government completely ignores the committee's opinion related to the individual complaint.

### **Women with disabilities**

### **14.**

The Swedish Disability Federation notes that the government does not respond to that part of the question concerning the involvement of children and women in processes to develop and implement policies, programs or in legislation. See also the commentary to question 6.

### **Children with disabilities**

### **15.**

The Swedish Disability Federation welcomes Handisam's and the Ombudsman for children's ongoing work. It is of great importance that the Handisam's inquiry of what children think and the children's ombudsman's work to identify methods to communicate with children with disabilities is followed-up. It is not enough that opinions are surveyed and methods identified. The results of Handisam's and the children's ombudsman's current ongoing work must be translated into practical tools for children with, for example



communicative disabilities to express their views in all matters affecting them.

Of great importance is also that children and young people learn about their rights. There are no description of the content of the CRC and the CRPD targeted to children with disabilities.

The Swedish Disability Federation is not aware of that the Government or any of these authorities have produced information material or by other means disseminated information about the meaning of Article 7.3., If Article 7.3 shall have an impact the meaning of the article must also be disseminated to all those who meet with children with disabilities.

Although the Committee do not ask any questions of taking children into care the Swedish Disability Federation will pay attention to the Committee that organizations highlight difficulties in the compulsory care of children with disabilities. We have seen many examples where a child has been taken into state custody due to that the social welfare services estimate that a child's behaviour are due to deficiencies in care. In fact, the behaviour of the child, for example autism has not got the right personal treatment at school and the parents did not receive support at home. Compulsory care is often given without first having tested support at home.

## **16.**

The Swedish Disability Federation is not aware of the criticism directed against the two awareness activities described in the Government's response. Article 8 requires immediate, effective and appropriate measures. The Swedish Disability Federation considers that the government's lack of a deliberate strategy to meet the requirements of article 8 and that the government can do much more to increase awareness about the human rights model of disability.

The Swedish Disability Federation also considers that the government needs to reduce the risk for offensive statements so-called hate crimes. The current regulatory framework does not prohibit describing people with disabilities in an offensive manner. The crime of incitement to racial hatred covers race, skin colour,



national or ethnic origin, belief and sexual orientation, but not disability.

## **Accessibility (art. 9)**

### **17.**

The Swedish Disability Federation is especially critical to how the Government has dealt with the question of inadequate accessibility and of complying with the laws connected to accessibility.

An overall problem in the field of accessibility is that the government lacks an overall progressive strategy to meet the Convention's different dimensions of overcoming barriers in society, including the perspective of Universal Design. The responsibility for achieving accessibility is divided between different ministries, stakeholders and authorities without having neither a clear strategy or being anchored in the Convention. The Parliamentary Committee on Transport Report<sup>1</sup> from 2013 shows, for example, the large gaps in accessibility since the transport responsibility was regionalised and deregulated.

The government's lack of respect for the Convention is clear in the Government Bill "More housing for young people and students" from 2013 in which the Government proposes exceptions to accessibility in wind residences and smaller buildings. The Council of State has questioned how the government interprets the exemption on the basis of the Convention. But the government has simply referred wordings on fitness in the Government Bill<sup>2</sup>.

Despite that the EU's disability strategy is based on requirements in the public procurement related to standardization, the assignment that was announced in the Swedish strategy concerning public procurement support has not been carried out. The Swedish Disability Federation considers that it requires vigorous measures to

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<sup>1</sup> [http://www.riksdagen.se/sv/Dokument-Lagar/Utedningar/Rapporter-fran-riksdagen/Hela-resan-hela-aret---En-upp\\_H10WRFR5/](http://www.riksdagen.se/sv/Dokument-Lagar/Utedningar/Rapporter-fran-riksdagen/Hela-resan-hela-aret---En-upp_H10WRFR5/)

<sup>2</sup> <http://www.regeringen.se/content/1/c6/23/05/25/45ca632f.pdf>



strengthen the knowledge on public procurement support to set and monitor the procurement requirements.

The government has not announced a plan for the review of shortcomings in legislation related to Article 9.

As shown in the alternative report, there are several gaps in the regulatory framework. Even though Sweden has ratified the CRPD in 2008, there are for examples still no requirements that public websites shall be accessible.

In many areas there are laws but as shown in the alternative report, there are deficiencies in compliance. There is a complete lack of sanctions if the regulations are not followed. Individuals who are prevented from participating in society because of shortcomings in accessibility do not have access to effective remedies related to Article 9. The government has now promised a bill which means that failure to take steps for accessibility could be considered as a ground of discrimination. Swedish Disability Federation does not know what the bill contains and has not been involved in the work.

### **Equal recognition before the law (art.12)**

#### **18 och 19.**

Administrator means a restriction of the right of individuals to act.

There is a reference to the information already sent to individual committee members in connection with the precession in September 2013, and the information submitted to the Committee of the organizations supplemented the Swedish Disability Federation\*s comments on the draft general comments on Article 12.

### **Access to justice (art. 13)**

#### **20.**

Disability Federation would like to mention in particular item 214 which shows that:



"The Administrative Court Procedure Act (1971:291) and the Swedish Code of Judicial Procedure prescribe that an interpreter should be used if necessary. Such laws also describe the translation to and from Braille. The Administrative Court Procedure Act has no equivalent concerning for example Braille. Laws cover information and communication for the parties, but the information is not made accessible for the members of a jury. "

The lack of knowledge about various disabilities and disability impeding factors such as lack of knowledge about the support people with disabilities are entitled to in connection with the different court processes is a major problem and creates legal uncertainty.

The Swedish Disability Federation has no further comments regarding the regulations. In practice, there are great difficulties. That the questioned understand the meanings of issues and the answers are correct interpreted is the basis of a fair trial. The Swedish Disability Federation welcomes therefore question 1 about E-training for the judiciary, but is very critical to that the Swedish Disability Federation has not been involved in the development of education.

## **21.**

The Swedish Disability Federation has no comments.

### **Liberty and security of the persons (art.14)**

## **22.**

The Swedish Disability Federation confirms the government's response.

Whether people with moderate intellectual disabilities are at risk of longer sentences because they for some reason recognize a crime with higher penalty scale is unknown.

## **23.**

**Information from prison services shows that:**



- Today a larger proportion of young people who commit crimes are brought to court, compared with ten years ago. Slightly more young than previously are sentenced to prison-like sanctions.
- A cross section/ a snapshot of what it looks like is on 1 October 2011, there were 189 young people in prison 15-20 years, which was 3.7 percent of the total number of inmates.

We don't know if these young people are separated from adults in practice. We have not been able to find a more recent report than from 2000 as presented in the Swedish Disability Federation's alternative report on Civil and Political Rights.

Autism and Asperger's Association has done a survey of all HVB home in Sweden who claims to accommodate children and young people with autism and Asperger syndrome. The report of the survey shows that only 15 percent of these are using autism-specific methods.

## **24.**

The Swedish Disability Federation notes that additional training for all those involved in the judicial system is necessary for people with disabilities to have a legally secured personal treatment. In a recent case where a young girl with Asperger's had been raped the police and prosecutors took into account the disability and held an adapted hearing. But the district court did not consider that the evidence met the process requirements of the legislation for a conviction because the girl did not tell sufficiently independently of the incident. That someone helps her to explain by asking questions in the courtroom does not mean that her story is less probable.

Conversely an autistic boy the upper teens was sentenced in all instances of child rape after having sex with an underage girl. But two of the Justices of the Supreme Court wanted to free. They argued that the boy lacked intent, because he due to his disability had difficult to understand what was wrong with his action. Here it





becomes clear that different judges look different on the impact of disabilities.

## **25.**

The Swedish Disability Federation has no comments on this answer.

### **Freedom from torture or cruel, inhumane or degrading treatment (art 15)**

## **26.**

Today there are no restrictions on how long you can have compulsory care. Three people had in 2009 compulsory care for 46 years.<sup>3</sup>

The head medical director decides if a person needs compulsory care. After a number of weeks, the physician must submit documentation to the Administrative Court confirming that the patient is in continued need of compulsory care. In 90.5% of the cases, the Administrative Court judges that the head medical director is right<sup>4</sup>. In 2012, Jan-Sept, it was 99,5 % of 200 ongoing decisions.

The legal position for a person with a psychiatric disability is therefore very doubtful.

Compulsory care is often a consequence of that it's hard to get help at an early stage. If such therapy had been more easily accessible, compulsory care cases would have been reduced.

In Sweden there are three legal compulsory care treatments: separation, belt restriction and forced medication. A person may be belt restrained in four hours and separated in eight hours. To extend the time a personal examination is required by a specialist in psychiatry.

It is remarkable that the largest group that are belt installed are women aged 18-34 years with a diagnosis listed as self-injury

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<sup>3</sup> [http://www.rsmh.se/Psykiatrisk\\_tvangsvard.pdf](http://www.rsmh.se/Psykiatrisk_tvangsvard.pdf)

<sup>4</sup> <http://www.svt.se/agenda/om-agendas-granskning-av-tvangsvarden>



behavior (according to a report that was produced in the project: Better care less compulsion). The law seems to be used in a wrong way. Belt installation should only be used in emergencies and in difficult psychiatric conditions, for example to be able to compulsory medication. These women would feel better with other types of treatment, such as various forms of therapies There is also a risk that belt installation becomes part in their self-injury behavior.

As regards separation, we have seen example of how patients "as punishment" have been separated / isolated in a bare room with a mattress on the floor as the only furniture and a glass of soft plastic with a little water in, as the only interior detail. Unjustified intrusion into the individual's correspondence and the opportunity to communicate with the outside world is often a reality that compulsory inmates must endure. Patients will normally not keep their mobile phones. If they can borrow a phone they are normally denied to borrow a phone directory.

They are denied even the opportunity to borrow pen and paper to write a letter or note a telephone number. Compulsory cared patients have sometimes had to use "illegal" methods, eg to smuggle out messages and other documents with visitors, for example to be able to get in touch with organisations working on the rights of persons with mental illnesses and disabilities. RSMH which is one of these organizations tells us that "When we tried to visit these patients, we have often been met with resistance not based on objective needs"<sup>5</sup>.

The government takes up the opportunity to get a support person, which was introduced in the law of compulsory treatment in 1992. But the fact is that most psychiatric activities in the country do not follow the law in this regard. The patient committees have over the years accumulated a considerable amount of information about the often striking shortcomings in how a support person is offered,

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<sup>5</sup> Källa: <http://www.rsmh.se/Handbok.pdf>



appointed and function without any reaction from the regulatory authority.<sup>6</sup>

The Swedish Disability Federation considers that a support person always shall be appointed at all types of compulsory care but the patient must of course have the right to say no to this effort. The support person should be able to accompany the patient during the transfer between types of care, such as from forensic psychiatry to prison service or a safeguard measure. The organisational difficulties with various organisers that arise can and needs to be eliminated.

The government also takes up the project Better care less compulsion, which is a project that the Swedish Disability Federation welcomes and which has given very interesting results, in the form of, for example, fewer belt installations. However, it is remarkable that while this project is implemented, the government is working in parallel with the introduction of proposals that would both help to seize persons to compulsory care and facilitate the implementation of coercive measures such as seat belt installations and separation. These proposals are in the Psychiatric inquiry SOU 2012:17. If the proposals in the report were to be implemented, it means an unacceptable return to the development of mental health services including an increased risk of arbitrariness for when force should be used.

In Sweden there is no inspection body that is controlled by patients, clients and relatives. Such control is desirable and models are available, for example in Norway.

## **27.**

In 2000 approximately 18,000 treatments were conducted with ECT in Sweden. That figure had in 2009 increased to 45,000 per year and in 2010 to roughly 40,000. The Swedish Disability Federation has noted with concern the ongoing increase - an increase that is matched by reductions in the number of qualified psychotherapies.

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<sup>6</sup> <http://www.rsmh.se/Yttrande-Psykiatrilagsutredningen.pdf>



The government claims that ECT is not possible to give without the patient's consent. But this is not true.

Every year the psychiatry reports a few hundred cases to the National Board of Health and Welfare that they have used ECT as compulsory treatment. The treatment is generally given to patients in deep depression, which means that they are passive and introvert. In such a state, you are not capable of doing physical resistance even if you are hostile to the method. So it is quite possible to implement ECT treatments despite the absence of consent, and the patient has said no.

Users and their relatives have also experienced that they in certain psychiatric practices are trying to force the patient to receive ECT, regardless of whether their treatment is compulsory or optional. ECT treatment is described by the health care as the only possible option, although other methods have not always been tested. That the health care is trying to force on the patient ECT is something the National Board of Health and Welfare noticed in a report in 2010.<sup>7</sup>

It is also difficult to appeal and get right when it comes to malpractice by electroshock and in health care in general.<sup>8</sup>

## **28.**

There is still a lack of facts and statistics about violence and abuse against persons with disabilities. It is rare that boys, girls, women and men with disabilities are mentioned in various contexts, but when they are it's usually as a homogeneous group. More knowledge is needed about the diversity that exists between people with disabilities.

The National Board of Health and Welfare conducted in 2012 a survey<sup>9</sup> of shelters in Sweden. Of the 206 that were inventoried 195 responded to a questionnaire. According to the survey, only 43

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<sup>7</sup> [http://www.svd.se/nyheter/inrikes/fler-behandlas-med-elchocker\\_4423495.svd](http://www.svd.se/nyheter/inrikes/fler-behandlas-med-elchocker_4423495.svd)

<sup>8</sup> <http://www.dagensmedicin.se/debatt/debattsvenska-patienter-ar-i-dag-rattslosa/>

<sup>9</sup> Socialstyrelsen, konsekvensutredning – förslag till föreskrifter och allmänna råd om våld i nära relationer, 2013



percent of the sheltered accommodations had the competence to accommodate people with mental disabilities. More than half of the support centers could accommodate people in need of a walker, escort or personal assistance. The National Board of Health and Welfare's monitoring shows that many municipalities have access to any form of support or sheltered accommodation but there are shortcomings in many municipalities because there is no accommodation for vulnerable groups such as abused women with disabilities.

Victim Support Association conducted a collection of statistics<sup>10</sup> on crimes against persons with disabilities for a trial period of six months in 2013. Five victim support centers participated, and these support centers receive support applicants from 19 municipalities. During the trial period the support centers had a total of 1766 cases. Of these, 1,426 people had an additional question if they had any disability. 218 said yes, representing approximately 15 percent. Most common types of crime were assault, molestation and unlawful threats. More women than men were exposed.

Development center Twice exposed conducted a survey<sup>11</sup> of 24 shelters in the region of Västra Götaland. Women's support centers rarely get requests from social services, adult psychiatry or support seeking women about the need for sheltered accommodation. The experience of the staff at shelters is that they to too little extent reaches out to women with disabilities, even though they know they are just as abused as women in general who are victims of violence. According to the Social Services Act, the municipality must provide abused women with disabilities the support and protection they need and the conclusion is that municipalities must take greater responsibility and provide resources to women's support centers to be accessible.

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<sup>10</sup> Statistikfråga på försök inom projektet Brottsutsatt och funktionsnedsättning 1 mars – 31 augusti 2013, Brottsofferjourernas Riksförbund, 2013

<sup>11</sup> Otillgängliga kvinnojourer – sant eller falskt? Bräcke Diakoni, Utvecklingscentrum Dubbelt Utsatt, 2008/2012



## **Living independently and being included in the community (art. 19)**

### **29.**

The last six years, the opportunity for people with severe disabilities to be entitled to personal assistance or other services under LSS (the Act 1993:387 on support and service for certain functional impairments) has deteriorated significantly.

The Swedish Disability Federation confirms the information sent to the committee from the relatives association for persons with mental disabilities based on Waldorf pedagogic care, [see link](#). The information clearly shows that municipal autonomy in practice has become superior to national law. The described court cases show also that the Convention has not had an impact on the practical work in municipalities and courts and the principle of an interpretation that conforms to the Convention is not in use.

The Swedish Social Insurance Agency's changed interpretation of the Act's wording on basic needs depends in terms of access to assistance mainly to a judgment by the Supreme Administrative Court, RAW 2009 ref 57. They made a very strict interpretation of what needs to be considered as belonging to the "basic needs" according to the 9 a § LSS. Those who are in need of assistance with basic needs for more than 20 hours per week receive state-funded assistance allowance while others may be entitled to assistance allowance from their municipality, if the basic needs are of the "right character and scope".

The consequence of the judgment has meant that it is now much more difficult for:

- People with severe disabilities to receive the assistance they need in order to meet even their most basic needs.
- Individuals to be able to qualify for state allowance that they can take with them wherever they live in the country and that is not affected by local differences.



The judgment has also led to the growing difficulties of those with less extensive disabilities to even grant assistance and "other personal needs" is assessed more restrictive with respect to persons whose basic needs are not considered to be 20 hours per week.

The Swedish Social Insurance Inspectorate has in a report on the outcome of decisions about state assistance allowance<sup>12</sup> noted that:

The picture as a whole is that assistance benefits through the year 2007 has had a steady increase in terms of both the number of recipients and granted hours per recipient. Thereafter, the number of persons decreased who were newly granted assistance with just over a quarter, while the number of refusals increased by nearly 50 percent in 2008. Relatively large changes have also occurred in the number of people who get their assistance-reimbursement withdrawn in a retrial. Despite the increase in cancellations, the level is low, at just under 2 percent for the year 2011.

In the above report indicates that the number of withdrawals is low. That it was 2% in 2011. If you look at the trend from 2010 onwards, however, the number of individuals who received their payment withdrawn is too high. The number of people who have had their personal assistance withdrawn from The Swedish Social Insurance Agency since 2010 amounts to over 1,000 people according to the Social Insurance's own statistics. How many of these who have received personal assistance from the municipality are unclear. What we do know is that most of those who receive assistance help get a reduction in the number of hours. Often is the cutback sharp.

We also know that the consequences for people who have had their personal assistance downsized or withdrawn often are devastating. There are several examples of people who have lost their jobs because they can no longer work after downsizing / withdrawal. Parents who are unable to function well in their parenting because they receive too little assistance. People who get stuck in their beds

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<sup>12</sup> Inspektionen för Socialförsäkringen, Rapport 2012:18, Utfall av beslut om statlig assistansersättning, Stockholm 2012, s 5-6

[http://www.inspsf.se/publicerat/Publikation+detaljvy/utfall\\_av\\_beslut\\_om\\_statlig\\_assistanser\\_sattning.cid3994](http://www.inspsf.se/publicerat/Publikation+detaljvy/utfall_av_beslut_om_statlig_assistanser_sattning.cid3994)



because they cannot get up or lie down when they want or people who cannot get out from their apartments.

### **30.**

The Swedish Disability Federation notes that the government does not answer the question whether there is a concrete action plan to increase accessibility to schools.

As shown in the alternative report, lack of accessibility to schools' premises poses a big risk that students with different disabilities cannot stay fully in school. Lack of adequate support is another factor that makes it difficult in the educational situation for many children and young people with disabilities.

A new aggravating factor in recent years is the Supreme Court's interpretation of the rules on additional amounts for children with severe special needs. The Supreme Administrative Court has ruled that additional amount need only be provided if the student has a comprehensive need for special support outside the educational situation (HFD 2012 ref 46).

This DOM has meant big problems for free schools that now have difficult to give the children the support they need, because they do not receive additional amounts for supportive measures in the teaching situation.

Some children with autism, for example, can not be in school because they did not receive sufficient support and sufficient adaptations. Often, the parent must then abstain entirely from work, sometimes resign from a job, to be home with the baby. Here arises because of this a situation where parents lose a lot of income, which they are not compensated for in any manner. The municipality does not compensate this despite that the lack of support lies on their responsibility. The allowance does not cover this cost. the Swedish Disability Federation considers that Sweden therefore violates both Article 24 and Article 28.





The Swedish Disability Federation also want to highlight the importance of that school yards and other areas related to the school are accessible and usable for students with different disabilities. Today there are no plans for how accessibility to schools and nearby areas will increase.

The Swedish Disability Federation would like to emphasize that a targeted approach by the school authorities is essential but not enough. The shortcomings of the framework must also be addressed. Children and young people's experience must to an even greater extent be utilized.

The Swedish Disability Federation also notes that the Government does not describe how teachers' skills on different disabilities and disabling factors will increase. Increased knowledge for all within the education system is necessary. Students' right to education must be viewed from a holistic perspective. It is not enough that a student with a disability receives a seat in a class. Students with disabilities must be included in all education and in all activities related to the school. This means that even those who are close to the teachers and students who have a disability must have an understanding of what may constitute a disability. This is also necessary to promote good personal treatment including both respect and consideration.

### **31.**

The Swedish Disability Federation confirms that some action has been taken in order to achieve a more equal care. The fast development in the area of health causes concerns when the digitization of services in health care risks to exclude people with disabilities who for various reasons do not have access to the Internet.

A major complication in the Swedish health care system is that the actual decisions about health care's scope and design is taking place at the local level.

One shortcoming that regards the vast majority of diagnostic groups, is the access to specialists. People with disabilities often need to



travel far to even be able to get access to appropriate specialist care. Within the public health sector several diagnostic groups are getting neglected. This includes people with mental disabilities. The following information has been prepared after the Alternative Report and is an indication of deficiencies within healthcare and medical treatment that urgently must be reviewed and corrected.

On average, people with mental illness are living about 25 years shorter than the general population. One cause is suicide. Another is body diseases treated successfully among the general population, but not for those with psychiatric diagnoses.<sup>13</sup>

In cardiac care, patients with psychiatric diagnoses wait longer for angioplasty than other patients, although acute heart attack was found at the same time.<sup>14</sup>

Regarding stroke, the results show that patients who had psychiatric diagnosis at the same time did not receive neck vascular surgery, a operation in order to remove calcification of the carotid artery, to the same extent as the other patients.<sup>15</sup>

Even when it comes to cancer and diabetes, people with mental illness have a higher mortality.<sup>16</sup>

## **32.**

Suicides and suicide attempts have not declined among young people since the alternative report was written. Rather, there are figures showing that young feel worse.<sup>17</sup>

People are not offered psychological treatment to the extent that would be needed, as National Board of Health and Welfare drew attention to this summer.<sup>18</sup>

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<sup>13</sup> (<http://www.dn.se/debatt/socialstyrelsen-kraver-battre-var-d-for-psyksjuka/>)

<sup>14</sup> <http://www.socialstyrelsen.se/publikationer2011/2011-6-15>

<sup>15</sup> <http://www.socialstyrelsen.se/publikationer2011/2011-5-3>

<sup>16</sup> <http://www.socialstyrelsen.se/publikationer2011/2011-6-22>  
<http://www.socialstyrelsen.se/publikationer2011/2011-2-5>

<sup>17</sup> <http://www.dn.se/debatt/socialstyrelsen-kraver-battre-var-d-for-psyksjuka/>



National helpline is a telephone line where people with suicidal thoughts have been able to call, is today threatened with closure because it lacks funding.

According to a report<sup>19</sup> by the Institute of Public Health, low income and low education are factors that cause increased risk of suicide,

Measures to raise the living standards among vulnerable groups is therefore necessary to reduce suicidality.

The Swedish Disability Federation notes that the last few years the most vulnerable have got it worse and worse - they are on sick leave - of which persons with mental illness is the largest group. Nor is there anything to indicate that efforts to reduce youth unemployment have succeeded.

The draft bill <sup>20</sup> from 2008 mentioned also that it will be easier to get therapy, but this summer National Board of Health and Welfare has criticized that the primary care does not offer psychological treatment to the extent that is necessary.

### **33.**

The Swedish Disability Federation can again note that the government has not responded to the question. In this context the Swedish Disability Federation is however concerned that the government lacks an understanding of what is meant by habilitation for adults.

The Swedish Disability Federation considers that the health care law's wordings are good but the related guidelines need to be developed in several areas. Generally there are good guidelines for rehabilitation for most diagnostic groups. As seen in the disability movement's alternative report national guidelines need to be

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<sup>18</sup> <http://www.dn.se/debatt/socialstyrelsen-kraver-battre-var-d-for-psyksjuka/>

<sup>19</sup>

<http://ki.se/content/1/c6/08/30/64/Underlagsrapport%20fran%20Statens%20folkhalsoinstitut.pdf>

<sup>20</sup> <http://www.dn.se/debatt/socialstyrelsen-kraver-battre-var-d-for-psyksjuka/>



reviewed and supplemented with guidelines for diagnosis groups where they do not exist.

As regards habilitation there are in many counties good habilitation activities for children but, rehabilitation services for adults must be developed.

Continuous monitoring of the habilitation rehabilitation offered in practice must be done regularly. The Swedish Disability Federation has experienced that it looks very different in this country.

### **Work and employment (art. 27)**

#### **34.**

The Swedish Disability Federation notes that the government has not responded to the question and that the gap between people with disabilities and people without disabilities continues to increase. Statistics from the Employment Service that compares to week 4 2014 to week 4 in 2013 shows that the number of unemployed has increased by 7.3 percent for persons with disabilities, while it decreased by 3.5 percent for persons without disabilities.

The Swedish Disability Federation would like to refer to the CRPD general comments No. 18 on work and labor emphasizing that States' commitments related to work and labor also include an obligation to create jobs. Further, Article 27 of the CRPD states that states shall "g) Employ persons with disabilities in the public sector."

The Swedish Social Insurance Agency report, "Ten years with activity compensation" (2012) shows that very few young people with reduced work capacity aged 19-29 have jobs. Despite the wording of Article 27, paragraph g, the proportion of young people with disabilities is lowest in the public sector. Of 12,938 young people with reduced work capacity were only 155 people employed by Government authorities and county councils! Most of the young people with disabilities were found in small, private companies.

The Swedish Disability Federation would also remind you that many things are interrelated. Lack of accessibility to workplaces and



difficulties for individuals who are dependent on housing adaptations and assistance to change their place of residence, are components which makes it difficult for individuals to take a job. The government requires that the individual must seek jobs across the country in order not to lose any unemployment benefits. This requirement is unreasonable to many people because access to the same or similar assistance, etc. are not guaranteed at the new place of residence.

The government inquiry of labor market programs for persons with disabilities (2012), shows shortcomings in the Swedish Public Employment Service. The methods of employment rehabilitation lack evidence base. There is no follow-up of the initiatives provided. Only a few come to work or study and a large number go around in different actions. The advisers who work with persons with disabilities have far fewer resources than those working with other groups of job seekers.

The time to have a disability identified and thus have access to various efforts, has increased and is now up to an average of 270 days.

Handisam's evaluation of the national disability strategy (2013) shows that it takes on average 86 days longer for a person of foreign origin to get a code of disability than for a Swedish person.

### **Adequate Standard of Living and Social Protection (Art. 28)**

#### **35.**

The Swedish Disability Federation would underline the importance of seeing the family's financial situation from a holistic perspective. Swedish Disability Federation refers to the information under Article 24, which shows the economic vulnerability of families with children with disabilities are exposed to as a consequence of, for example, that the school doesn't function.



## **Participation in political and public life (art. 29)**

### **36.**

The Swedish Disability Federation has no comments to the government's response.

### **37.**

The Swedish Disability Federation has no further comments-

### **38.**

Still there are not possible to vote on a special candidate in secret if you are blind. For more information see article 29 in the alternative report on CRPD.

### **39.**

The Swedish Disability Federation has no further comments-

### **40.**

The Swedish Disability Federation lacks knowledge of what difficulties politicians with different disabilities can have before and after the election. (the electoral process). The Swedish Disability Federation would emphasize the importance of seeing that the real possibility for individuals to be elected and participate in the political process must be viewed from a holistic perspective. For example, that accessibility to association premises and places for political exercise as well as access to accessible information and communication are crucial for people with disabilities to participate fully in all aspects of the political and electoral process..

The Swedish Disability Federation's view is that failure to take action to already legal requirements for accessibility must be considered discrimination (see the comments to question 17).

A holistic perspective must also include the possibility in practice to get to and from meetings, which includes transportation services, as well as access to and the right to personal assistance, escorts and interpreters based on individual needs.



The Swedish Disability Federation would especially mention an illustrative case that we consider to be inconsistent with the Convention. A woman who, because of her disabilities needed a personal assistant that was present at the committee meetings. At a meeting, January 18 2011 arose a question if the assistant could be present at meetings when the committee would deal with cases where secrecy prevails. After a discussion the assistant had to leave the meeting. After this meeting, they have not sent documents home to her as to the other members. In order to read documents before the meetings she must instead go to the social administration. The case was reported to the Ombudsman but was left without remark.<sup>21</sup>.

The woman was forced to resign as opportunities to prepare herself completely disappeared.

#### **41.**

Handikappförbunden har inga ytterligare kommentarer men vill återigen understryka vikten av att information görs tillgängligt.

### **Specific obligations**

#### **Statistics and data collection (art.31)**

#### **42.**

The Swedish Disability Federation has no comments

#### **International cooperation (art.32)**

#### **43.**

The Swedish Disability Federation notes that the Government has not responded to the question. Therefore no further comments

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<sup>21</sup> <http://www.jo.se/PageFiles/1216/710-2011.pdf>



#### **44.**

The Swedish Disability Federation considers that the government not answered the first part of the question because the government does not specify in what way they want to mainstream the disability perspective.

Regarding the second part of the question, we recognize from the Sida reports<sup>22</sup> that some parts have been implemented but with a strong delay. These include the development of guidelines, policies and country strategies. The part that deals with professional development of Sida staff centrally and in the field with the assistance of a disability movement has completely been lost.

The Swedish Disability Federation notes that the Government has been influenced by our views and financed the participation of representative from the disability movement both at the recent state party meeting and at the high level meeting in 2013. The Swedish Disability Federation hopes this is a new practice that will last.

#### **National implementation and monitoring (art. 33)**

#### **45.**

The Swedish Disability Federation considers that much more needs to be done to the perspective boys, girls, men and women with various disabilities should be taken into account in a satisfactory manner within the Cabinet Office.

The Swedish Disability Federation are not completely satisfied with the order to have an authority, Handisam, which coordinates the implementation of policies across a wide range of authorities.

One consequence of this is that the relevant ministries in our opinion does not fully take responsibility for the disability issues.

The Swedish Disability Federation also questions that the coordination responsibility lies under the Ministry of Social Affairs, instead of the inter-department in the Prime Minister's Office, or the

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<sup>22</sup> [http://www.sida.se/PageFiles/31597/12664\\_Kartl%25C3%25A4ggning\\_PWD\\_web.pdf](http://www.sida.se/PageFiles/31597/12664_Kartl%25C3%25A4ggning_PWD_web.pdf)





Ministry responsible for Human rights and discrimination issues (in Sweden, ie the Ministry of Labour)

Regarding cooperation with the disability movement refers to question 5.

**46.**

Sweden still does not have a national institution of human rights as it is described in article 33. As may be seen under point 585 in the alternative report, the report from the Delegation of human rights in Sweden gives proposals on "A New structure for protection of human rights", SOU 2010:70.

In 2011, the civil society and the authorities had opportunities to submit comments and suggestions on the proposals.

A Letter on Human rights are announced until 18 March 2014.

The Swedish Disability Federation notes that the Government once again choose to work with a weaker tool in the form of a government letter instead of the a bill that must be addressed by the Parliament.

Mentioned letter has not been communicated with civil society.  
If you have questions, please contact:

[Annika Jyrwall Åkerberg](#)

Lawyer in Human Rights

Best regards,

**THE SWEDISH DISABILITY FEDERATION**

A handwritten signature in black ink that reads "Ingrid Burman". The signature is written in a cursive, flowing style.

[Ingrid Burman](#)

President