

**Swedish disability movement's alternative  
report to the UN Committee on the Rights of  
Persons with Disabilities**

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Facts, analysis and text: Annika Åkerberg  
Year of publication: 2011  
ISBN: 978-91-86151-15-7

## **Swedish disability movement's alternative report to the UN Committee on the Rights of Persons with Disabilities**

The aim of the report is to provide the Committee with an overall view of how Sweden complies with the UN Convention on the Rights of Persons with Disabilities. The report includes also recommendations by the disability movement of how the situation could be improved.

The report shall be regarded as a complement to Sweden's first official report to the UN Committee on the Rights of Persons with Disabilities. The report complies with the guidelines of how the State report shall be presented in order to facilitate comparisons between the reports.

A total of 50 disability organisations support the report as well as 7 other HR-organisations, see annex 1.

The report has been submitted to the Swedish Government in April 2011.

### **Project Agenda 50 – tools for our rights**

#### **SWEDISH DISABILITY FEDERATION**



Ingrid Burman  
President

#### **SWEDISH ASSOCIATION OF THE VISUALLY IMPAIRED**



Tiina Nummi-Södergren  
President

#### **FORUM WOMEN AND DISABILITIES**



Karin Hjalmarsson  
President

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Karin Westlund  
President

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## **Introduction**

1. Sweden signed the convention on the rights of persons with disabilities on 30<sup>th</sup> March 2007. Following this, the work to ratify the convention began. The disability movement has been involved in all parts of the ratification work and finds the collaboration between the government and the disability movement very satisfactory. But we are concerned about the results of the collaboration.

2. At an introductory stage, the government launched an inquiry into Sweden's possibilities to ratify the convention. The opinions of the disability movement have been acknowledged in the inquiry. Both in the memorandum Ds 2008:23 "The UN Convention on the Rights of Persons with Disabilities" and in the following government bill "Human rights for persons with disabilities"(bill 2008/2009), it is noted that much work remains. (page 8). With the exception of launching an investigation concerning article 33, definite measures to reinforce rights for persons with disabilities have not been taken in a satisfactory way. As can be seen in article 4 of this report, neither has the convention made an impact on research concerning persons with disabilities.

## **A new strategy**

3. Sweden has had an action plan for "disability policies" from 2000 to 2010. The organisations that represent disabilities were invited to partake in the evaluation of the action plan and had the opportunity to give general views on a future strategy. Subsequently, the government decided, in keeping with the thoughts put forward, that the convention on the rights of persons with disabilities shall be the starting point for a strategy and that the strategy shall cover five years.

4. The government then decided on nine objectives for the strategy. These have since been broken down into different sub goals. In order to incorporate the disability movement's organisations' opinions about the sub goals, Handisam, (Swedish Agency for Disability Policy Coordination) distributed a questionnaire (the time span for answers was very short) to all the organisations represented by The Swedish Disability Federation and Equally Unique, The Swedish Federation, Human Rights for persons with disabilities. Handisam also arranged a forum for discussion to which all organisations were invited.

Currently, a draught is being prepared at the Ministry of Health and Social Affairs. A preliminary time for the presentation of the strategy is April/May 2011.

5. The disability movement consider that there should have been decidedly more thorough collaboration. The organisations should have been invited to partake in all parts of putting together the strategy. In-depth dialogues should have been implemented concerning how the strategy ought to deal with especially neglected areas such as inadequate accessibility. It is particularly notable that neither the government's nor the disability movement's reports to the UN's supervisory committee were finished before the goals were defined.

## **The disability movement therefore considers that:**

The UN committee should commission the Swedish government to give parliament an account of how the recommendations from the disability movement shall be handled.

## **Disposition**

6. This report keeps to the structure of the convention. For an overall picture of the respective rights, we recommend the reader to take part of the information pertaining to each article of rights.

**For every article there are the following parts:**

- A. Description of the regulatory framework
- B. The disability movement's comments on the regulatory framework
- C. Comparative statistics and results of research
- D. The disability movement's comments on the actual situation
- E. The disability movement's recommendations about the measures the Swedish state should take in order to live up to the contents of the convention. All recommendations are found in annex 2.

All articles also include analyses of structural obstacles as well as monitoring and outcomes.

The report uses many abbreviations. A list of those used will be found in annex 4.

## **Summary and overall comments**

7. This report shows that there is still a lot to be done before persons with disabilities can participate on equal terms in Sweden. The disability movement has views in connection with all the rights articles. However, there are structural inadequacies within the following three pivotal areas that are significant for the implementation of the convention in Sweden.

### **The regulatory framework is not followed**

8. A general conclusion is that Sweden has good laws within many areas, but the laws are not complied with. Ensuring that the regulations are abided by is a huge challenge but crucial to the realisation of the convention's rights. The disability movement is especially critical of how the government has dealt with the question of inadequate accessibility and complying with the laws connected to accessibility. Much of the work and the decisions that are necessary to achieve better accessibility for persons with disabilities have been postponed to a later date. We note with considerable dismay that the government has not taken more measures for accessibility after the convention has been ratified.

### **Inadequate interpretation of the convention**

9. As seen in article 13 of this report the convention has not been incorporated into Swedish law. Interpretation conforming to the convention has been used instead – authorities and courts interpret laws so that we live up to the convention. Authorities' and courts' lack of interpretation that conforms to the treaty, inadequate knowledge about disability and its consequences and individuals' human rights are other significant reasons that explain why individuals do not receive the equal support and service that they are entitled to.

### **Lack of efficient legal remedies**

10. In Sweden the Discrimination Ombudsman (DO) can with 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 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<sup>1</sup> and can be invoked in a court of law. As seen in article 13, knowledge about disability and human rights is often inadequate among the personnel of courts. This may lead to individuals with disabilities having less opportunities than others to access efficient legal remedies in connection with all the rights in the convention. DO can, within the framework of a charge revoke The European Convention, but cannot pursue a case that rests only on it. The disability movement considers that Sweden must ensure that individuals receive equal support and access to efficient legal remedies in connection with civil and political rights as with economic, social and cultural rights. It should be possible for DO to pursue cases that are based solely on the European Convention.

## **Summary conclusion**

**11.** The disability movement wishes to conclude by pointing out that even though several important measures have been carried out, the obligation to plan society so that it includes all and is accessible has not taken root, despite the obligation having existed for decades. Society planning must seriously start to shape an environment that includes all for sustainable development and future growth. Despite laws that have been in use for decades, the same mistakes are made in the planning of activities and environments. Instead of including the varying needs of all citizens at the outset, long-term investments are still made that, because of the inherent inadequacies, will lead to costly (and less functional) special solutions in the future.

## Article 1 Purpose

12. The Swedish disability movement has no points of view concerning which groups are included in the concept “persons with disabilities”. We show below, therefore, only certain statistics about the occurrence of disabilities.

The National Survey of Public Health<sup>2</sup> from 2009, presents the following figures: 23 percent of the population (16-24yrs) have a disability. This is the equivalent of 1.5 million people. The total population is more than 9.5 million people. The number of people with disabilities increases with age. Among the youngest, 16-29yrs, about 10 percent had a disability. In the oldest age group, the corresponding percentage was 40.

10 percent of the population of 16-84 year olds (more than 650 000 people), are hard of hearing, 4 percent (more than 250 000 people) are partially sighted.

8 percent (more than 500 000 people) have reduced mobility.

3 percent had more than one of the disabilities of sight, hearing and mobility.

About 3 percent, 230 000 people, have grave anxiety problems. If those with lesser problems were included, it would amount to almost 18 percent. Psychotic conditions occur in 1.5 percent of the population. Some need qualified hospital care. 15 percent of 75 year olds have psychiatric diagnoses such as depressive, anxiety and psychotic syndromes. If persons who do not have a diagnosis but who show signs of significant mental health problems and experience daily suffering are included, it is estimated that every fourth 75 year old is in need of some form of care due to mental ill health.

In 2008, the number of persons with dementia was estimated to be 140 000, 11 500 of whom were under 65yrs of age. The number of persons with dementia in each age group is doubled in five-year intervals after the age of 65. Among 60-64 year olds it is 1 percent. Almost half of persons who are 90 years old suffer.

About 38 000 people have learning difficulties.

Every year, between 60 000 and 70 000 Swedes suffer acquired brain injuries. Most can be divided into two categories – strokes and injuries in connection with trauma. Every year about 30 000 people suffer from strokes, 20 000 of these for the first time. The average age for men is 73 and for women 77. About 100 000 of those who have suffered strokes are alive today. No less than 20 000 need substantial assistance and round-the-clock care. Strokes are the most common reason for disabilities among adults. More than 30 000 people a year suffer a traumatic brain injury. By a low estimate, more than 200 000 people live with some form of acquired brain injury.

4 percent (more than 200 000 people) aged from 16 to 84 have diabetes.

About 60 000 people have epilepsy and about 20 000 of these suffer badly.

7 percent, about 470 000 people have asthma to varying degrees.

About 30 percent of school children have ongoing allergic diseases (asthma, rhinitis, eczema, food allergy or other reactions to exposure to allergens).

5 percent, about 330 000 people, have heart diseases.

About 5 percent have recurrent severe stomach/intestine problems.

It is estimated that between 5 and 8 percent of Sweden’s total population have dyslexia, specific reading and writing difficulties. Many have difficulties of a lesser nature.

About 25 000 people have speech impediments (dysartry). There are about 3 000 new cases every year.

About 70 000 adults have stammering problems.

About 5 percent of all children have speech and language disorders during childhood. 1-2 percent suffers from severe speech and language disorders.

About 5 percent of all school children have ADHD. Many still have difficulties as adults, although the difficulties may be expressed in a different way.

It is estimated that between 1 500 and 2 300 children have autism (2-3 per thousand). The corresponding number for Aspergers syndrome is 3-4 per thousand. Significantly more have autistic features.

Almost 10 percent of the total population use assistive devices to compensate a disability<sup>3</sup>.

## **Article 2 Definitions**

### **Communication**

**13.** The convention's definition of communication is well known to Handisam (Swedish Agency for Disability Policy Coordination), the government's staff and expert authority with special responsibilities to coordinate disability policy. However, there are shortcomings in the practice and understanding of communication among both public and private players. Neither is there any obligation for public players to provide information, or to communicate, in a medium or method chosen by, and applicable to, the individual, for example Braille or digital, see articles 9 and 21.

### **Language**

**14.** According to the Language Act, Swedish sign language is equal to the five national minority languages. The act stipulates that the public sector has a special responsibility to protect and promote Swedish sign language. However, the government's information campaigns for municipalities and relevant authorities promoting the Language Act and national minority languages, have not included Swedish sign language. Although it is now on an equal basis with national minority languages, Swedish sign language fell between two stools, the ministry for integration and equality that limited its information campaign to the five minority languages, and the ministry of health and social affairs that has the overall responsibility for disability policy.

### **Discrimination on the basis of disability**

**15.** There is no general ban against discrimination related to disability. Protection against discrimination exists only in connection with areas covered by the European Convention on Human Rights and Freedoms and The Discrimination Act (see articles 5 and 9, items 42 and 156). The ban against discrimination includes all types of discrimination. Obligations to take reasonable measures of accommodation exist only in connection with work and education. Neglect to take measures for accessibility is not seen as discrimination under the law. Prohibiting discrimination because of disability is not written into the Swedish constitution's Instruments of Government (Regeringsformen). Regeringsformen's provisions cannot be referred to in the law courts, but no other laws or ordinances can be in conflict with its provisions.

### **Reasonable accommodation**

**16.** Reasonable adjustments and accommodations are undertaken to safeguard that persons with disabilities enjoy or may practice human rights and freedoms on an equal basis with others, and they are of crucial significance. There is still a lot to be desired in this area. In keeping with articles 2 and 5, there is a need to extend obligations to make reasonable accommodations to other areas than work and education.

### **Universal design**

**17.** Universal design is an attitude and a process, a starting point for planning and design that is based on human diversity instead of the "average person". The national plan of action for disability policies from 2000, stipulates that this starting point is the goal for how society's different parts should be fashioned.

The goal that universal design should permeate public-sector undertakings within architecture and design has, however, not been reached. On the contrary, we have seen how it has been lost in the process; when we have pointed this out over the years we have not been met with understanding. We can see that conceptions are not clear, and that the vision of the end result is confused with how to think.

18. The Disability Movement's recommendations, see annex 2

### **Article 3 General principles**

19. This report, similar to earlier alternative reports on economic, social, cultural, civil and political rights, finds that it is not always the case that the principles listed in article 3 are recognised and permeate Swedish case law, other exercise of public authority or municipality decisions.

#### **COMMENT**

- Taking note of the 8 principles is a prerequisite for the implementation of the convention.

20. The Disability Movement's recommendations, see annex 2

### **Article 4 General obligations**

21. As can be seen in this report there is still a lot to be done before persons with disabilities enjoy equal access to their human rights as others. The Swedish government also notes this in the bill<sup>4</sup> concerning Sweden's ratification of the convention. The disability movement's recommendations as to how the situation can be improved will be found in annex 2. A general conclusion is that Sweden, in many areas, has good legislation but the laws are not always abided by in practice. This is the case for example within the area of accessibility. (see article 9).

22. The national action plan for disability policy has appointed 14 sector authorities that have special responsibilities to promote disability policy goals within their sectors/areas. All government authorities also have special responsibilities to render their premises, information and activities accessible for persons with disabilities. Despite this, Handisam's questionnaire from 2010<sup>5</sup>, finds that authorities' knowledge of the meaning of accessibility is inadequate in all aspects of functional ability. Only one in four authorities (24%) has organised study courses about accessibility for their personnel over the last three years.

23. Handisams questionnaire to authorities notes that having an action plan generates a positive effect. It finds meanwhile that one in three authorities still lacks a plan, thus failing to live up to its responsibilities for the development of policies for disabilities as laid down by the government. There is work to be done by all authorities of all ministries, but especially by the authorities of the Ministry of Justice and the Ministry of Enterprise, Energy and Communications.

24. Whether Sweden's ratification of this convention has contributed to public investigations and national norms including greater recognition of human rights of persons with disabilities is not clear. The disability movement notes that some central inquiries have taken the convention's wording as their starting point, among these the study "Bortom fagert tal" about inadequate accessibility as grounds for discrimination. The outcome of the study was that inadequate accessibility should be judged as discrimination. It is still very unclear whether the suggestion will

be apprehended, see article 9 item 156. We have noted that other inquiries and surveys name the convention but it is hard to see how it permeates suggestions or is a starting point for an investigation. Unfortunately, we also note that the convention is not mentioned at all in surveys that directly affect persons with disabilities. An example of this is the survey of special schools<sup>6</sup> in 2011.

## **Research**

**25.** Research opportunities are good in Sweden. For research in connection with universal design, factors pertaining to disabilities or reduced abilities, there is adequate funding. But research is about not with those who are the subject of the research being undertaken. Because of this, The Swedish Disability Federation's organisations are currently engaged in a three-year project to recruit co-players for research into disability. Unfortunately, the project notes that over the past few years, representatives from civil society in research councils have been reduced, which means less insight and opportunity to influence the content of research.

## **26. COMMENT**

- Significant measures must be taken to ensure that the convention is implemented at every level of society. When doing this, the recommendations in this report should be noted.
- Ways of ensuring that the existing regulatory framework is complied with must be introduced. This is a great challenge but a pivotal part of the work to implement this convention.
- All official government reports that concern human rights must refer more distinctly to the appropriate convention or right. Moreover, reports that affect persons with disabilities must always reflect this convention's general principles.
- Financial backers of research should be encouraged to demand representatives from civil society in research councils and that research should involve those who are affected by it.
- A closer proximity between research and society must be encouraged. The government can point research in a certain direction, for example, through various programmes and campaigns and by promoting the importance of interdisciplinary research of disabilities.
- Organisations in civil society should be given the opportunity, in collaboration with universities, to apply for research funding.

## **Article 4 item 3 Consultation with the disability movement**

**27.** Of crucial significance to increased enclosure is the collaboration of the various players in society with the disability movement. Concerning consultation at a national level there are, according to Handisam's questionnaire to authorities from 2010, considerable shortcomings. Only one third (35 percent) of those who responded had established contact with the disability movement when working to make the authority accessible. It is an increase compared to the survey of 2008 but a slight decrease from the one in 2007 where 38 percent said they had established contact.

**28.** The Swedish Disability Federation notes that the disability movement is always contacted to consider new legislative proposals and can thus comment on implemented reports and suggestions. The disability movement is not, however, involved at all in compiling directives for official reports. Neither is the disability movement invited to contribute to reports as specialists and experts. Examples from 2009/2010 are the survey of social insurance where a "rehabilitation council" was appointed but the disability organisations were refused a seat; the delegation for the Swedish Inheritance Fund, writes the government in its annual report, includes representatives of prioritised groups, but there is no one from the broad spectrum of the disability movement and the government has no plans to review the delegation's constitution; the Dental and Pharmaceutical

Benefits Agency has shut down its user council - the list of times when the disability movement has been left out is long.

**29.** Collaboration at a local level is written into a few laws that specifically oblige municipalities to work together with the local disability movement. This is the case with the Act concerning Support and Service for persons with Certain Functional Impairments, section 15:” The duties of a municipality include (...) collaboration with organisations that represent people with extensive functional impairments.” The demands on a municipality are however limited by the range of the laws.

**30.** A survey carried out by Sweden’s Municipalities and County Councils, SKL, in 2008, found that nearly all of the municipalities that had responded to the questionnaire work together with disability organisations. Four in five municipalities had an accessibility plan and 94 percent of the municipalities said that they have a formal disability council. In the municipalities that had an accessibility plan, or the equivalent, 89 percent of the disability councils had assisted or voiced opinions about the plan. About 60 percent of municipalities had routines for lodging complaints about accessibility.<sup>7</sup>

**31.** According to the Ordinance on Government Grants, organisations may receive grants. The aim of government grants is to support organisations with their work for full participation and equality in society for persons with disabilities. The disability movement confirms that the government grant has increased but by so little that it does not cover inflation over the past few years. Moreover, the grant is not increased when more/new organisations are added. This means that organisations that have had grants before, find their grant decreases when new organisations are added. This can create unhealthy competition.

**32. COMMENT**

- The wording of the convention that the convention states shall closely consult with and actively involve persons with disabilities through their representative organisations puts pressure on the various parties of society to embrace the experience and expertise inherent in disability organisations.
- If organisations are to meet the increasing demand, grants must be raised, extra funds made available for new organisations and regulated remuneration for activities that call for expertise.

**33.** The Disability Movement’s recommendations, see annex 2

## **Article 5 Equality and non-discrimination**

### **Article 5 1. Equality before the law<sup>8</sup>**

**34.** There are still laws in Sweden that discriminate against people with disabilities. Here are some examples:

**The Education Act ( Skollagen SFS2010:800 )**

**35.** The principle guideline is that the state provides education for all young people at all levels. However, the wording of the new Education Act (for example chapter 10, § 30), permits schools to refuse admission to pupils who require extensive extra resources. (for further information see article 24.)

**The Penal Code (Brottsbalken) chapter 16, § 8,agitation against a national or ethnic group**

**36.** The provisions in The Penal Code concerning agitation against national and ethnic groups are more limited than those parts of the Constitution that regulate Freedom of Expression. The current system of rules does not ban describing people with disabilities in an offensive manner.

The crime “agitation against national and ethnic groups” covers only grounds for discrimination against sexual orientation and ethnicity, not disability.

#### **The Act on Genetic Integrity (Lag 2006:351 om genetisk integritet)**

**37.** The Act gives insurance companies the right to seek out and make use of genetic information when insuring adults for large sums of money (lump sums of 1,2 million or periodic payments of 160,000 SEK per year.) In practice, these rules mean that people with disabilities due to genetic inheritance cannot take out such policies. In spite of the fact that people with disabilities due to genetic inheritance run the same risks as others of meeting with accidents, being run over by a car, an icicle dropping on their heads etc, and must have the same right to take out an insurance policy.

#### **Laws in the area of work**

**38.** Many of the laws that involve workers’ safety contain elements of legal inequality. For example The Aviation Law,( Luftfartslag 1957:297), Law on Safety in Metro and Tramway, (Lag 1990:1157 om säkerhet vid tunnelbana och spårväg), Professional Transport Act (Yrkestrafiklag 1998:490), and Maritime Safety Act (Fartygssäkerhetslagen 1988:49) Further information can be found at Article 26 of the alternative report on political and civil rights.

#### **The Diseases Act (Smittskyddslagen , lag 2004:168)**

**39.** With the current wording of the law, people with, for example, HIV risk being isolated against their will in a manner that seems incompatible with Article 14. For further information, see Article 14 item 242.

#### **The Social Security System and people over 65 years of age**

**40.** People who get a disability after the age of 65 do not have full access to support and service or to social and economic security. For further information, see Article 28 item 522.

#### **41. COMMENT**

- A review of the regulatory framework must be carried out and the shortcomings described above rectified so that all people, regardless of age, sex and disability enjoy equal protection under the law.

## **Article 5 2. Protection against Discrimination**

### **Swedish Non-discrimination laws**

**42.** The prohibition of discrimination on the grounds of disability is laid down in “Regeringsformen” (Instrument of Government), which is part of the Swedish Constitution. Regeringsformen’s provisions cannot be referred to in the law courts, but no other laws or ordinances can be in conflict with its provisions.

To further reinforce the ban on discrimination laid down in Regeringsformen, there are two supplements, The Discrimination Act and The Law of the European Convention on Human Rights and Fundamental Freedoms. These two laws together contain prohibition against discrimination relating to most of the Convention’s articles. However, Article 9 lacks any protection against discrimination, see Article 9. The European Convention’s protection is in some respects narrower than its writings, for example in Article 29.

#### **43. COMMENT**

- Sweden must revise its non-discrimination laws so as to insure that all sections concerning rights incorporate prohibition of discrimination.

### **Non-discrimination and public service contracts**

**44.** The government decree (2006:260) concerning non-discrimination requirements in public service contracts prescribes that certain large government authorities must insert non-discrimination conditions in their negotiations. The aim of the decree is to increase awareness and observance of the Discrimination Act.

#### **45. COMMENT**

- The government decree is a step in the right direction. Similar regulations should be included in all the public services regardless of the level or nature of the sector. Public funds should not be used for activities that do not meet with Sweden's international commitments.

#### **Lack of effective legal redress**

**46.** Many of the Convention's rights are also found in The European Convention of Human Rights and Fundamental Freedoms. The European Convention has been incorporated into Swedish law<sup>9</sup> thus allowing it to be cited in a court of law.

As shown in the alternative report concerning civil and political rights (Articles 14 and 2), many bodies, including the law courts, lack knowledge of disabilities and human rights. This could lead to individuals with disabilities having less chance of acquiring access to effective legal means. The Discrimination Ombudsman, DO, can, with no charge, help individuals with settlements and court cases. The DO can only pursue cases in relation to the Discrimination Act and The Parental Leave Act (Föräldrarledighetslagen). These laws cover, largely, only economic, social and cultural rights. Within the framework of such an action, the DO can also invoke the so-called European Convention, but, cannot pursue a case that is solely based on it.

#### **47. COMMENT**

- People with disabilities must have equal access to effective legal means regardless of which of their rights they feel has been violated.

#### **Right of Action for Organisations**

**48.** The Discrimination Act gives organisations the possibility to represent a member in a court of law. This possibility has, however, not yet been tried.

#### **49. COMMENT**

- The risk of losing a case, thus having to pay for all the costs pertaining to it, means that disability organisations do not dare to pursue members' cases in the law courts. Sweden should therefore consider introducing legal aid also for organisations.

### **Article 5 3.**

#### **Adjustments for reasonable accommodation**

**50.** The law banning discrimination states that employers are obliged to make reasonable accommodations to ensure that job seekers and employees with disabilities enjoy an equal situation with others. Institutions of higher education have similar obligations. There are no such obligations to provide adjustments for reasonable accommodation within other areas.

#### **51. COMMENT**

- Banning discrimination without demands to ensure valid support and accommodation, except for the labour market and, to a certain extent, education, cannot be seen as sufficient if Sweden wants to live up to Article 5 3

**52.** The Disability Movement's recommendations, see annex 2

### **Article 6 Women with Disabilities**

#### **Regulatory framework and general equality work**

**53.** Regeringsformen, (Instrument of Government) part of the Swedish constitution, states that "No act of law or other provision may imply the unfavourable treatment of a citizen on grounds of gender, unless the provision forms part of efforts to promote equality between men and women or

relates to compulsory military service or other analogous official duties.”(Cases where other laws and other national regulations provide equal protection but which in fact distinguish because of gender are described in the relevant article of rights.)

Discrimination because of gender or gender identity is prohibited according to the Discrimination Act. Discrimination because of gender is banned also in the European Convention of Human Rights.

**54.** The government bill, 2005/06:155, stipulates the current aims for equality policies. The overall goal is that women and men shall have equal power to shape society and their own lives. The bill contains four interim objectives:

- Equal division of power and influence between women and men. Women and men shall have the same rights and opportunities to be active citizens and to shape the conditions for decision-making.
- Economic equality between women and men. Women and men shall have the same opportunities and conditions with regard to education and paid work that provide lifelong economic independence.
- Equal distribution of unpaid care and household work. Women and men shall take the same responsibility for household work and have the same opportunities to give and receive care on equal terms.
- Men’s violence against women must stop.

**55.** Considerable resources have been allocated to the work for gender equality over recent years . Also work for equality integration has increased, that is activities aimed at implementing the government’s equality policies. Examples of complementary activities are the action plan to combat men’s violence against women , the action plan against prostitution and people smuggling, research programmes about women’s health, efforts to integrate equality into municipality activities, and the work for equality carried out at schools as described in article 24.

**The gender perspective is often missing**

**56.** A report from the National Board of Health and Welfare<sup>10</sup> finds that there is very little known about whether men and women with disabilities are discriminated against because of their gender. The National Board notes that even recent studies about persons with disabilities lack a gender perspective. Persons with disabilities are seen in research and surveys as “genderless”. The National Board of Health and Welfare notes that the main influence in their lives seems to be disability.

In the second follow-up report about the national action plan for disability policies from 2006, the government notes that a challenge for the work ahead is spreading knowledge and methods to develop both a child and gender perspective within disability policy.

**57.** Sweden’s municipalities’ and county councils’, SKL, survey<sup>11</sup> over how work to protect women is organised in municipalities, county councils and regions, shows that equality activities and the protection of women are seen as more or less two separate areas.

**58. COMMENT**

- Analyses and discussions of disability policies have not included the power structures that exist between men and women. The lack of gender and equality perspectives for persons with disabilities adds to the invisibility of women with disabilities.
- The implementation and monitoring of activities carried out as equality policies and disability policies must always include the perspectives of gender and disability.

## **Statistic comparisons and research results**

**59.** However, certain special studies have been carried out and some limited information is available:

**60.** A report<sup>12</sup> from the Swedish Trade Union Confederation (LO), a collaboration of 14 unions, finds that of those who have reduced work capability, more women than men are unemployed. At the same time, more men than women enjoy labour market policy support. LO notes that the government should authorise the Employment Service to investigate how this has come about and how it can be rectified.

**61.** Statistics from the Social Insurance Office show that it is twice as difficult for women as for men to find acknowledgement of work injuries. Women's problems are not seen as work injuries and this leads to less money from the social insurance. Only 13 percent of women's applications for life annuity due to work-related ill health were granted in 2006 compared to 26 percent of men's.<sup>13</sup>

This means that women lose money more often than men when they are injured at work, because the annuity is designed to compensate loss of income for an injury that causes permanent damage. 72 percent of the women were refused compensation 2006 because their injuries were not considered to be caused by work. Svend Erik Mathiassen, professor at the Centre for Cumulative Trauma Disorders, university college Gävle, says that one reason for this is that women and men are exposed to different types of injury. Women often have monotonous repetitive jobs that cause diffuse pain. This makes it difficult to point to the reason for the pain with any certainty, says Svend Erik Mathiassen and adds that most international research into strain injuries has been about heavy lifts as they are common in men's working environments. Because there is no research into how repetitive lesser strain affects the body, women receive no acknowledgement of their pain as work induced. The Social Insurance Office also mentions inadequate research as a reason why women do not qualify for life annuity. The law states that there must be scientific evidence and known factors about the injury. If these are not in place, there is nothing we can do, says Monica Svanholm, head of the department for work injuries at the Social Insurance Office.

Also women who are exposed to heavier strain, for example healthcare personnel, find it difficult to get acknowledgement for pain as a work injury. Anne Marit Överby, spokesperson for matters of insurance at the union Kommunal, appeals decisions from the social insurance authority all the time. She says that most difficult are injuries that appear after many years of heavy lifting and moving patients about.

**62.** According to the Environmental Health Report 2009 (National Board of Health and Welfare et al) more women than men find indoor environments detrimental to their health; 60 percent of women between the ages of 18 and 80 say that they have some health trouble at least once a week because of the indoor environment at school or at work, compared to 11 percent of men. 14 percent women react badly or very badly to smells, perfume, cleaning fluids or printing ink compared to 7 percent for men. 11 percent women say they have had eczema of the hands during the past 12 months, compared to 8 percent of men.

Many of the discrepancies between men and women concerning environmental ill health can be explained by different exposure. It is more common for women to be employed in healthcare and medical service and this means they are more likely to suffer work-related illnesses such as asthma, allergies, skin trouble and infections.

**63.** Since the revision of the Social Services Act in 2007 in order to clarify social services committees' obligation to heed crime victims' need of support and assistance, especially women and children who have witnessed crimes, many measures have been taken. The National Board of Health and Welfare has, for example, presented general advice<sup>14</sup> and instruments for assessment. The measures taken encompass all women, regardless of municipality, who have been exposed to violence, vulnerable groups too, among which we find women with disabilities. The national survey carried out in 2008-2009 by the Board of Health and Welfare and the county councils, however, found that many municipalities lack sheltered housing for women with disabilities who are exposed to violence.

**64. COMMENT**

- Methods to highlight, document and abolish the many cases of discrimination within all policy areas and levels of society must be developed further
- There is no treatment today of oversensitivity to smells/perfumes and people are obliged to avoid the substances they are sensitive to – which can be hard. There is a need for knowledge and training about how to show respect and make it easier for persons who are oversensitive. There is also a need of more research into treatments.

**65.** The Disability Movement's recommendations, see annex 2

## **Article 7 Children with disabilities**

**66.** Parliament has approved a strategy<sup>15</sup> to reinforce the rights of children. The strategy takes its starting point from the Convention of the Rights of a Child and includes various principles to be used as guidelines for parliament, government, government authorities, county councils and municipalities, which in the course of their duties, shall safeguard the rights of a child. The strategy states that municipalities and county councils should devise systems for the purpose of monitoring how a child's best interests can be achieved in the work of the municipality. The strategy states that municipalities and county councils are responsible for most of the activities in children's lives and for safeguarding their rights.

**67.** There are many regulations that relate to children with disabilities, for example laws related to schools and to healthcare and medical service. The children's ombudsman has a special duty to observe that laws and other regulations, and their interpretation, are in keeping with the children's convention and suggest amendments and other measures that are needed.

### **The Regulatory framework**

**68.** Laws covering specific rights are described in the respective articles. Here only laws of a more general character are described.

**69.** According to the Social Services Act (2001:453 SOL), municipalities' social services office shall strive to oversee that all children living in the municipality grow up under secure conditions. Special attention must be given to children who are at risk of developing in a manner that is harmful to them. A child's best interests must always be the focus. If a child is at risk of coming to harm, it is the duty of social services to advise and support both child and parents and, if needed, arrange care and treatment. Should it be thought for the best that a child is cared for outside the home, social services arrange this. When social services hear of a child that might need support or protection, it is their duty to start an inquiry to assess the needs of the child. (SOL 11:1). People, who in the course of their work come into contact with children and young people who might need support or protection, are obliged to report and give details to social services (SOL 14:1).

**70.** If social services decide that a child needs care outside its own home, but the child's guardian or the child itself – after the age of 15 – refuses, the county administrative court can, alerted by the social welfare committee, pass judgement according to the law Care of Young Persons (LVU). Both child and guardian in such cases have the right to public counsel.

**71.** Guardians who have extra costs of living because of a child's disability or ill health, or if a child needs special care for at least six months, are entitled to attendance allowance. The allowance is available from the time the child is born up until 19 years of age. The allowance is given to the parent who applies for it, or the person who has legal charge of the child. It is possible for two parents to share the allowance. In such cases the parents must however be in agreement, or the allowance goes to the person who has custody of the child. Attendance allowance is also given to a person, or persons, who care for a child before adopting.

**72.** The regulatory framework concerning support and service for persons with disabilities (Social Services Act, SOL) and the Act concerning Support and Service for persons with Certain Disabilities described in articles 19 and 23, item 2, also covers children. The Swedish disability movement's alternative report on economic, social and cultural rights, articles 10 and 11, notes that municipalities and county councils do not always implement all the decisions made in support of the legal rights of children with disabilities. In the summer of 2006 the law was amended. Municipalities who do not within a reasonable time limit comply with a legal decision as stipulated in the Social Services Act are obliged to pay a special depository fee of up to one million Swedish kronor. The same applies to a municipality that does not implement a court decision.

**73.** Children's right to learn sign language is laid down in the Language Act. See items 360-362.

**74. COMMENT**

- The ombudsman for children's duty to highlight the implementation of children's rights and assess that the perspective of the UN convention on the rights of a child is maintained, is an important part of the work to promote the rights also of children with disabilities.
- The shortcomings of the regulatory framework, or its implementation, as seen in articles 9, 12, 12, 19, 20, 24, 26 and 30 need to be addressed in order that children with disabilities have equal opportunities as other children to participate in society.
- Both parents of a child with disabilities must be able to receive attendance allowance even when they are not in agreement.
- An equal system of sanctions is needed for cases when the provisions of LSS are not implemented. All children, regardless of degree of disability must have equal opportunities to have their rights catered for.

**Coordinating activities**

**75.** Many children and young people with disabilities need support from different areas of society to develop their skills. Activities may be arranged by pre schools, schools, habilitation services for the young, sight and hearing resource centres or some other activity. A report<sup>16</sup> from the National Board of Health and Welfare in 2010 concerning parental support, notes the following shortcomings and needs concerning families where children or guardians have disabilities:

1. The responsibility to coordinate activities needs to improve, for example between municipality activities and schools
2. Families' influence is inadequate
3. Information passed on to parents, children and personnel is insufficient
4. There is a need of more research into parenting and disability

The report confirms the information included in the Swedish disability movement's alternative report on civil and political rights (article 23) and the alternative report on economic, social and cultural rights (article 10) where more information can be found.

The Swedish National Audit Office is currently carrying out a survey on how public players' coordination of support for children with disabilities can be rendered more efficient within the framework of funds allocated for this purpose.

#### **76. COMMENT**

- Coordination of activities related to children with disabilities is of crucial significance for the provision of their rights and to enable family life to work. Necessary measures to make life easier for these families must be taken forthwith.
- Instruments designed to follow up delegated and joint responsibility of municipalities and county councils must be introduced, to safeguard that all girls and boys with disabilities are given the right to care, habilitation, rehabilitation, support and service indiscriminately.
- The obligation that exists, according to the National Board of Health and Welfare's guidelines, for county councils and municipalities to coordinate habilitation and rehabilitation should also apply to pre schools and schools. Children with disabilities spend a great deal of their day at pre school or school and in order for that to work in the best possible way there must be a legal obligation to collaborate with supportive public authorities, county councils' habilitation and municipality resources. For the best of a child it is important not to divide life up into different areas of authority, a holistic approach is better.

#### **Inadequate enforcement of laws**

##### *Access to pre schools and schools*

**77.** In Sweden it is common for children to attend pre schools while their parents are at work. It is considered of the greatest importance that schools, pre schools and after-school facilities are designed to promote children's development. Pre school and school activities are covered by the new Education Act, described in article 24. There is no comprehensive picture of how pre school activities cater for children with disabilities. There is however some limited information:

**78.** A survey carried out by the TV4 news channel in 2009 asked the country's municipalities if they had special pre schools or other facilities for children who are exceptionally allergic. Two thirds (68%) said they did not. 63% thought there was no need because childcare was arranged in alternative ways, for example private day carers. Unfortunately, the Swedish Asthma and Allergy Association receives calls from a number of parents every year, saying that their municipality has not succeeded in solving the problem of childcare in a satisfactory manner for children with severe allergies.

**79.** In 2009 The Asthma and Allergy Association looked into how pre schools and schools were supervised in 16 municipalities regarding the indoor environment. Over half of those contacted said that they lack the resources to carry out supervision. In some municipalities few or no supervisory visits are made – the only visits there is time for are those responding to alarms/complaints. This means that a child can spend its whole childhood in a facility that the municipality has not checked to see if it complies with the provisions in the Swedish Environmental Code. The quality of the indoor environment of schools and pre schools varies according to where a person lives because supervision is not the same in the whole of the country,

**80.** The Swedish Association of Hard of Hearing People note that a good hearing environment for children (especially the hard of hearing) is of crucial importance because their language is still developing. Municipalities' implementation of current regulations concerning pre schools and

schools sometimes means that children who are hard of hearing cannot be given a place at pre school or school when they need it. Pre school and after-school facilities are not obliged to abide by the provisions of the environmental code concerning good sound environments.

**81.** As seen in article 24, there are shortcomings concerning both the regulatory framework and the implementation of rules covering schools. Accessibility of children's playgrounds and access to cultural activities and products is described in article 30.

#### **82. COMMENT**

- The regulatory framework concerning children's acoustic environment at pre schools, schools, after-school facilities and premises for leisure activities must be reviewed and reinforced.
- There are good laws covering many areas but as shown in articles 9, 24 and 30 they are not always complied with. The consequences of this are that children with disabilities do not enjoy their human rights on an equal basis with other children.
- The follow-ups of children's access to habilitation, assistive devices, healthcare and medical service must take into account the diversity of children with disabilities. The alternative reports on economic, social, cultural, civil and political rights note that the gender perspective is often lacking when surveys of children's and young people's living conditions are carried out and facts and knowledge are therefore inadequate.

#### **Child poverty**

**83.** Save the Children has highlighted child poverty in Sweden since 2002. The organisation's eighth report<sup>17</sup>, presented in February 2011, accounted for child poverty in 2008. 220 000 children lived in poverty in 2008 – that is to say 11.5 percent of all children in Sweden. This is the highest number since the surveys started. There are significant differences of levels of poverty around the country. There are also differences among groups of children depending on whether they live with a single parent or parents living together, whether the parents were born in Sweden or abroad, or whether the children live in one of the segregated suburbs outside the cities. 18.1 percent of the children in Borlänge live in households that receive income maintenance or have low standards of income. Child poverty is 31 percent in Malmö, in Täby 3 percent. In the Malmö suburb of Rosengård it is 61.4 percent, in Torslanda, a city borough of Gothenburg, it is 2 percent. 49 percent of children with a single parent who has an immigrant background live in economic poverty. The report does not show how many of these families have members with disabilities. However, studies have noted a connection between poverty and, for example, school results, place on the labour market, health, bullying and security in the home area.

#### **84. COMMENT**

- Children cannot support themselves and are thus dependent on the income of their parents. Fees for healthcare or assistive devices can hit really hard, for example a hearing aid, batteries, and technical devices for hearing and specialist fees. All extra costs of living, not just the outstanding ones that occur in connection with parenting a child with disabilities, must be covered.

#### **Children taken into care**

**85.** The children's ombudsman has asked all the social welfare committees in the country whether they have their own directives for the process of taking children into care and their placement in new environments. Results show, among other things, that only one fifth of the committees have their own directives for the procedure when wrongdoings in a family or residential care services come to light. The investigation to redress the wrongs done to children, Upprättelseutredningen, that was presented to the government in February 2011, has listened to over a thousand adults who

as children were taken into care by authorities in order to secure a safe childhood. The outcome however was neglect and suffering. The study notes that abuse and grave negligence occurred to an unacceptably high degree and does so in public institutions of care even today, and there is surprisingly little awareness of the problem. The study has also monitored social services' knowledge of the misconduct taking place in public care facilities as well as their routines for coping with misconduct. The study shows that social services knew of a total of 246 children who from 2008 to 2009 were probably victims of abuse or neglect. Most of the cases were severe. This number however says nothing about the actual occurrence. The study finds that documentation and routines for the discovery and handling of misconduct were very rare. No methodical work was carried out to gather and analyse facts of this nature. About 20 000 children and young people in 2005 were taken into some sort of custody under the provisions of the Social Services Act or the Care of Young Persons law.<sup>18</sup>

As seen in article 9 of the Swedish disability movement's alternative report on civil and political rights, the National Board of Institutional Care has highlighted the fact that it is common that these children have neuropsychiatric disabilities, often ADHD. The information in articles 14 and 22 of this report note that children who are placed in family homes or institutions under the provisions of LVU are at greater risk of having, in many ways, a disadvantaged childhood.

#### **86. COMMENT**

- Institutional care for young people must be evaluated and developed so that young people receive the support they need
- Existing methods of care and habilitation in connection with mental or neuropsychiatric disabilities must be used

#### **Article 7.2 The best interests of the child a primary consideration**

**87.** The Swedish Association of Hard of Hearing People notes that economic priorities, inadequate knowledge and attitudes are put before the needs of children. Children are placed in environments where those with disabilities have no opportunities to participate. This is sometimes the outcome of legal decisions or other regulations, (see article 24), sometimes of inadequate knowledge and attitudes of those implementing the regulations or those responsible for the activities.

Good conditions in noise-sensitive environments and accessibility for children (especially those hard of hearing) are crucial because their language is developing. When a child's understanding (because of vocabulary and knowledge) is limited, it is more difficult to fill in the gaps if it cannot hear. Despite this, many children do not receive the assistive communication devices they need and it is not standard procedure to fit children's hearing aids with telespool cords. There is usually a lack of assistive communication devices and their maintenance is not guaranteed. Children do not always receive assistive communication devices for use during leisure time<sup>19</sup>.

#### **Sign language**

**88.** About 1 – 2 per 1000 children a year become deaf, deaf-blind or hard of hearing. It is estimated that there are about 10 000 children who are deaf, deaf-blind or hard of hearing between the ages of 0 to 2 years. All county councils provide hearing screening at maternity units. A control is carried out after consent from parents. If a test indicates hearing problems, new tests are done after remit to an audiologist.

According to section 14 of the Language Act all people who are resident in Sweden have the opportunity to learn, develop and use the Swedish language. Also that:

1. A person who belongs to a national minority group is given the opportunity to learn, develop and use the minority language, and

2. A person who is deaf or hard of hearing or a person who for some other reason needs to use sign language is given the opportunity to learn, develop and use Swedish sign language.

Section 14.2 also includes the families of for example hearing children. Parents' opportunities to learn sign language is described in article 23, item 3.

#### **89. COMMENT**

- The method used to discover children's hearing problems is good. The subsequent activities such as care, habilitation and the opportunities to learn sign language are also good. However, guardians make decisions about activities on behalf of their children. But lack of knowledge about what a child's hearing problem may entail, and attitudes in society, often point decisions in the wrong direction (for example where a child does not have access to sign language and/or special schools). Thus, a child's best interests are not always the primary consideration.
- Parents must receive information about Swedish sign language when the first screening reveals hearing problems. In the same way parents to children, who in connection with the health control of three year olds, have, after a "language screening" been found to have late speech development, should be informed about sign language and alternative communication. All these children must be given places at pre schools that focus on Swedish sign language for the deaf or hard of hearing and the Swedish language for those with language problems.
- All children must be given the right to learn Swedish sign language as a subject regardless of the sort of school they attend (see further article 24 items 424-425).

**90.** Assistive devices in pre schools and schools are prescribed to the children which means that the school/pre school must bear the costs for adjustments and assistive devices that are needed for school activities. Schools do not always in these cases see to what is best for a child's development because economic priorities limit the choice of devices that are necessary and helpful. Pre schools tend not to seek advice and support very often from the National Agency for Special Needs Education and Schools and because of this children may have greater difficulties in developing social skills and participate less than other children of the same age.

#### **91. COMMENT**

- The progress of children with disabilities shall not be dependent on whether pedagogues are competent to seek support, as this does not always serve the best interests of children.

#### **The deportation of deaf children**

**92.** Sweden's actions are in direct confrontation with the UN Convention of the Rights of a Child in connection with the deportation of families where one or more child is deaf, hard of hearing or deaf-blind. Sign language is a necessity for all children who are deaf or severely hard of hearing and enables them to communicate safely and securely.

Children have the right to speak their minds in all matters that affect them. Children and young people are sometimes deported to countries where the possibilities of being taught by, and learning sign language at school, and having access to technical assistance are non-existent.

#### **93. COMMENT**

- The Aliens Act must be revised and amended so that children with disabilities cannot be deported to countries where they cannot gain access to facilities necessary to enable them to partake on equal terms with others.

## **Article 7.3 Children's views**

**94.** The joint project of The Swedish Disability Federation and the children's ombudsman, "Egen Växtkraft", includes a questionnaire sent to personnel that work to support children with disabilities. The answers show that although the activities are for them, children are seldom involved when decisions are made about planning and design. There is little information especially for children.<sup>20</sup> Just a fourth of the personnel, mainly from habilitation and play therapy facilities, say that they have designed special material for children. A little more than half of the personnel say they can provide interpreters if the need occurs. Not all centres can provide interpreters for children. About half of the personnel say they have specific ways of preparing for the meeting with child and parents. Only a fourth say that they have access to specialist literature for preparation. The majority of personnel record children's views in case files. Staff of interpreter centres and play therapy facilities however are not obliged to keep records and do not make notes. A fourth of the personnel say that there are written guidelines concerning children's participation, mainly personnel from habilitation facilities for children and young people; but also from audiology centres, centres for the blind and partially sighted and from facilities for play therapy. Altogether, the results of the questionnaire disclose that there is a long way to go before children's right to express their views becomes reality. The project found that the two most significant areas for development were knowledge about children and how to communicate with them, and supporting parents so that they can support their children's independence.

**95.** An ongoing project, Rullstolsmobility (wheelchair mobility), run by the National Agency for Special Needs Education and Schools and the university of Örebro, in collaboration with SRF and RBU, notes that coordinating diverse activities increases opportunities for this group to participate in daily life. If all those in contact with children are aware of children's rights to be heard and to take part in decisions about things that concern them, routines will emerge that emphasise their participation. This systematic way of working with target groups does not exist in many places around the country.

**96.** The Disability Movement's recommendations, see annex 2

## **Article 8 Awareness-raising for persons with disabilities**

### **Article 8 2.A Measures for awareness-raising**

#### **Raising public awareness**

**97.** All the associations that have responded to Agenda 50's questionnaire concerning how Sweden lives up to the convention, point out the lack of knowledge about different disabilities and factors related to disabilities they find among the general public and private and public parties in society. Sweden does not have a well-grounded strategy to promote and raise public awareness. One exception however is the ongoing 2010-2011<sup>21</sup> campaign in connection with Handisam's task concerning attitudes to mental ill health.

#### **Raising awareness about individuals and their families**

**98.** All public bodies that exercise authority – government, regional and municipal administrations – have an obligation to keep individuals and their families informed. The Administrative Procedure Act states, "that each authority shall provide information, guidance, advice and similar assistance to all persons concerning matters falling within the scope of its functions. The assistance shall be given to the extent that is deemed appropriate with regard to the nature of the matter, the person's need of assistance and the activity of the authority." Other special laws include more detailed obligations. One example is the Act concerning Support and Service for Persons with Certain Functional Impairments that states the municipalities shall 1.

continually follow up to ascertain who is covered by the act and their need for support and service, 2. do what it can to ensure that persons have their needs satisfied, 3. give information regarding objectives and means relevant to the activities according to this act.

#### **99. COMMENT**

- Sweden has not yet had a breakthrough for the fact that it is shortcomings in society that create disabilities. Thus there is a need for more information campaigns. We welcome the ongoing information campaign to raise knowledge about persons with mental disabilities and are of the opinion that similar information campaigns must be implemented in order to raise knowledge about the diversity among persons with disabilities. Information campaigns must include “invisible” disabilities.
- In 1995 electro sensitive persons were recognised as a “group with a disability” in Sweden. Despite this, their situation and needs of most of society’s activities are ignored. Measures to raise awareness about electro sensitivity must be taken so that the public and the authorities and other public players begin to respect persons with electro sensitivity.
- A prerequisite for the success of work to raise knowledge and change eventual misconceptions is good basic knowledge. As seen in article 31 there is a lack of knowledge and statistics in many areas. Research in connection with disability must therefore be encouraged.
- Disability associations point out that they are contacted by members who feel that they have not received information about the activities that are available in society. A survey of the way in which the authorities that have an obligation to inform carry out their duties should therefore be implemented.

#### **Raising awareness about rights**

**100.** Handisam was authorised by the government in 2010 to help municipalities and county councils implement the convention of rights for persons with disabilities. In collaboration with the Swedish disability movement’s project “Agenda 50”, Handisam has compiled a compendium for discussions in municipalities and county councils and arranged 11 regional conferences.

**101.** Agenda 50 is a three-year project funded by The Swedish Inheritance Fund, and the aim is to implement the convention of rights for persons with disabilities in Sweden. Agenda 50 has compiled educative material in 2 different areas and also material that makes suggestions for how municipalities, county councils and regions can work with the convention. Agenda 50 has regularly implemented study courses and taken part in various conferences and seminars concerning human rights. These activities have taken place at municipalities, county councils, regions and government authorities as well as for the disability movement. The project has a network where representatives from different associations can learn more and discuss questions about human rights. The project has also supervised the training of instructors for the various associations so that knowledge is passed on to the members of the organisations.

**102.** In March 2006 the government appointed the Delegation for Human Rights in Sweden to support, over a limited period of time, the long-term work to ensure full respect for human rights in Sweden. The task of the Delegation has been to support government authorities, municipalities and county councils in their work, devise and implement strategies for the increase of information and knowledge about human rights among different target groups and stimulate public debate about human rights. Representatives from community organisations are one of the Delegation’s reference groups. The Swedish Disability Federation does not have a representative in this reference group despite our repeated requests.

**103.** For 2011 Handisam is authorised by the government to gather knowledge and methods from the work to change attitudes on the labour market, regarding persons with disabilities that cause

reduced work capacity. The aim is to construct a knowledge base and a guide that can be of use in connection with work to change attitudes on and around the labour market.

#### **104. COMMENT**

- Establishing the perspective of human rights in relation to persons with disabilities has proved to be a very slow process. To achieve a breakthrough for the perspective of human rights so that it informs all activities in the public sector and the work of the disability movement, significantly more efforts are needed for the transfer of knowledge and methods.
- Project Agenda ends in July 2011. The disability movement must receive support to continue to develop knowledge and methods for work with human rights.

### **Article 8 2. B Raising awareness in the education system**

**105.** The Swedish Schools Inspectorate's survey<sup>22</sup> of the situation in 33 schools where there are pupils with visual, hearing and mobility disabilities, found a lack of understanding of the pupils' various prerequisites and abilities. In some schools there are pupils too, who have little understanding of pupils with disabilities.

**106.** The Swedish National Agency for Education has examined a sample of school textbooks to find out to what extent and in what way they detract from the core values of the curriculum, and has looked especially for signs of discrimination or other forms of insult. One version, Disability's (in)visibility in school textbooks (2007) notes that not only textbooks but also curricula sometimes miss the opportunity to highlight equal treatment of persons with disabilities.

#### **107. COMMENT**

- The organisations of the disability movement agree with the conclusion reached by the National Agency for Education that there is reason to work towards raising awareness about disabilities in steering documents and school textbooks. If Sweden is to live up to the content of article 8, work must be carried out by all parties to raise awareness within the new administrative structure in the field of education.

### **Article 8 2.C Medias' portrayal of persons with disabilities**

**108.** Media researcher Ylve Brune has carried out a close survey of how and to what extent the question of human rights has been presented and described in Swedish media between 2000 and 2006. Brune found that women, immigrants and persons with disabilities are to varying degrees invisible, or are usually presented in a context where they are found to be inadequate or threatening. Crimes committed by dominant groups against the inferior are hidden away: crimes against women, discrimination, crimes of hate, neglect to create public environments that are accessible for all people and more<sup>23</sup>. More recent studies about how media portrays persons with disabilities have not been implemented.

The few earlier Swedish studies<sup>24</sup> note that persons with disabilities are almost invisible in news bulletins and that reports maintain the picture of persons with disabilities as "them", an outsider group, that differs from the "us" group that represents the societal norm. The manner in which persons with disabilities are portrayed seldom varies; they are usually victims or heroes. Surveys show that the fact that persons with disabilities live different lives in different ways is never really portrayed. Another common connection in news bulletins is that between mental disability and violence<sup>25</sup>.

**109.** In the most recent study of public service, the researcher was keen to mirror the whole of the population in the report, and mentioned among others, persons with disabilities as part of a diverse

society. But when the transmission licences were finally signed, the 55 percent target was included, which means that only where, in the country a programme is produced is measured, but includes nothing of how the population is reflected.

**110.** Section 10 of the code of ethics for the press states that race, sex, nationality, occupation, political affiliation or religious persuasion in the case of the persons concerned should not be emphasised if such particulars are not important in the context and are disparaging. Nothing is said of disabilities.

**111. COMMENT**

- Independent, regular surveys of how the media mirrors the population are of crucial importance. The current popular journalistic methods of portraying deviances have negative consequences for persons with disabilities.
- The code of ethics for the press should cover disability.
- Persons with disabilities need to be included in all available media and in the production of media to ensure a comprehensive portrayal of diversity in society.

## **Article 8 2.D Awareness-training programmes**

**112.** As is seen in several of the articles in this report, inadequate knowledge among decision makers still leads to new obstacles for participation. The rights of the individual are not always respected because of authorities' inadequate knowledge in their course of duty. Article 13 shows, for example, that lack of knowledge in the judicial process causes legal insecurity.

**113. COMMENT**

- All universities, higher institutions of education and other vocational training courses that have a crucial effect on how the rights of an individual are respected and how society is fashioned, such as lawyers, journalists, teachers, jobs in healthcare and medical service, public transport as well as training that relates to built-up environments, information and communications, must include the perspective of persons with disabilities and disability factors.
- Comprehensive vocational training courses must be developed.
- Supplementary training for the employed must be encouraged.

**114.** The Disability Movement's recommendations, see annex 2

## **Article 9 Accessibility**

### **Article 9 1.A Buildings and Transportation**

#### **Physical environment – regulatory framework**

**115.** According to The Act on Technical Requirements for Construction Works (Lagen om tekniska egenskapskrav på byggnadsverk), new buildings and extensions must be made accessible for persons with limited abilities of movement and orientation capacity.

**116.** The Planning and Building Act (Plan-och Bygglagen) lays down the general rules for the physical environment. In built-up areas the environment must be adapted to suit persons with limited abilities of movement and orientation capacity.

**117.** The Planning and Building Act contains an obligation to remove easily rectified obstacles in public places and on public premises thus affording access for persons with limited abilities of movement and orientation capacity.

Accordingly, Building Regulation (BFS) 2003:19, stipulates that lack of textual displays and inadequate sound environments must be addressed. Owners of buildings are responsible for overseeing that easily remedied obstacles are rectified.

**118.** Legislation concerning accessibility to buildings applies when new buildings are being planned, are under construction or are subject to alteration. However, the regulatory framework needs supplementing so that houses for persons with disabilities are assured a higher level of accessibility. The rules for existing housing areas are also inadequate. Access to common areas is, for example, not regulated at all.

**119.** According to The Environmental Code (Miljöbalken), owners of buildings are responsible for making sure that their building does not endanger health through moisture, mould or faulty ventilation. The law, as stated in the preamble, incorporates persons who are slightly more sensitive than others. This leads to situations where the law is interpreted and found not to apply to persons with asthma and allergies, who are considered so much more sensitive than others that additional measures cannot be taken.

**120.** A Regulation concerning government authorities' obligations towards persons with disabilities, states that all public venues, information and activities must be accessible for persons with limited abilities of movement and orientation capacity. The regulation also stipulates that authorities should compile plans of action for their work with accessibility.

**121.** According to the Education Act (Skollagen), all children and pupils must have access to education. The school organisers are responsible for the school buildings, but there is no detailed regulation concerning physical accessibility.

**122.** The Environment Act (Arbetsmiljölagen), is to prevent ill health and accidents at the workplace and to otherwise achieve a good working environment. The employer is obliged to make reasonable accommodations regarding the workload or other suitable adjustments in order to suit the special needs of the employee. According to section 6 of the Provisions of the Work Environment Authority on workplace design, AFS 2009:2, workplaces, work premises and personnel facilities must, if needed, be accessible and useable for employees with disabilities.

**123.** According to Sweden's election laws, municipalities must use accessible polling stations. Exceptions can be made in collaboration with the county council.

**124.** Regulations concerning emergency exits for vacating premises do not stipulate accessibility for persons with limited mobility or orientation capacity. In the proposal for the new Planning and Building bill, it is prescribed that it must be made for persons caught in a building on fire, to get out or to be saved in some other way (chapter 3 section 9 item 4). However, note is not taken here of the variation of disabilities.

**125.** The Tobacco Act, which regulates, among other things, no smoking environments, does not, on the whole, cover the outside environment or houses. The right to demand smoke-free areas such as entrances to public buildings, open-air restaurants, platforms, balconies and common areas in apartment buildings does not exist.

#### **126. COMMENT**

- The current regulatory framework concerning accessibility in buildings for persons with limited mobility and orientation capacity is essentially good. The problem is that the rules are not

abided by. The perspective of accessibility and for persons with various disabilities, and universal design, must be systematically in place from the first planning phase, if accessibility is to improve.

- Many of the laws concerning accessibility relate only to persons with limited mobility and orientation capacity. This leaves out all those others in Sweden who are covered by the convention. The regulatory framework must therefore be revised, loopholes identified and amended.
- A revision of The Planning and Building Act, the proposed new bill and building regulations concerning the design of housing, must be carried out to ensure that all new housing and housing that is being rebuilt is made accessible and usable for persons with various disabilities. The regulatory framework for existing housing must also be revised.
- Persons with asthma, allergies or some other over-sensitivity must be protected by law, on an equal basis with others, against subjection to ill health caused by moisture, mildew and faulty ventilation. A revision of the regulations and instructions of the Tobacco Act, the Environmental Code and the Planning and Building Act must be carried out.
- Instructions for defining what is meant by accessibility in school environments are needed (see further Article 24).
- The Swedish National Board of Housing, Building and Planning (Boverket) needs to define what is meant by bad hearing/good sound environment according to the instructions concerning easily remedied obstacles.

### **Statistical comparisons and research results**

**127.** Below are several summaries concerning accessibility to buildings where there is mandatory legislation to take measures to ensure accessibility.

**128.** Only 6 of 271 authorities meet all the demands of accessibility for persons with disabilities. Authorities are obliged to meet 13 criteria, 214 authorities do not meet even half of the criteria. Despite demands that authorities put together plans of action to systematically cater for accessibility to premises, information and communication, and to render activities accessible, a third have not yet done so, after ten years work. More than a third of the authorities have not appointed a coordinator to oversee the improvement of accessibility. About seventy authorities have gone backwards in their work for accessibility.<sup>26</sup>

**129.** Two of three primary schools and half of secondary schools lack automatic door openers<sup>27</sup> (included in easily remedied obstacles).

**130.** Every fourth polling station at the 2010 election was not accessible to wheelchair users.<sup>28</sup> Only 56 percent of the polling stations at the election to The European Parliament in 2009 were wholly accessible.<sup>29</sup>

**131.** Only half of the institutions for culture that were approached said that wheelchair users could use the lobbies, toilets and auditorium without assistance. A fourth say that their premises are only partially accessible. A third of the institutions say that they have some form of tactile or contrast marking in the public parts of the premises. Half of the institutions have a loop system, or the equivalent, in operation on the premises.<sup>30</sup>

**132.** Houses, schools and childcare centres, built in the 1970s and 1980s, were found to have serious mould contamination. The reasons for this were, among other things, new and unproven building materials. Between 1983 and 2007, many homes received subsidies to remedy moisture and mould damage caused by technical inadequacies. The Swedish Agency for Public

Management (Statskontoret) in the subsequent report “Sega Gubbar”, showed that the quality had not improved and that many of the measures suggested in the survey “Skärpning gubbar” had not been implemented. Mould contamination and moisture damage are detrimental to all people but make life particularly hard for persons with allergies and those who are oversensitive.

### **133. COMMENT**

- Sweden must ensure that the regulations in place are abided by.
- Education in connection with building environments must include accessible buildings and universal design.
- Housing developers must be encouraged to use authorised accessibility consultants.

### **Transportation – regulatory framework**

**134.** The right to access to public transport for persons with disabilities is laid down in the Special Transport Act (Lagen om handikappanpassad kollektivtrafik) and in a subsequent Regulation, the latter more explicit in how accessibility should be achieved. Section 2 of the Regulation states that adjustments are made how and when it is judged reasonable to those using transport.

**135.** The regulations of the European Parliament and Council apply in Sweden, among these (EG) number 1371/2007 about rights and obligations for train travellers.

**136.** Buildings connected with travel are subject to the general building regulations described in item 115.

### **Statistical comparisons and research results**

**137.** A questionnaire<sup>31</sup> concerning perceived accessibility to transportation among persons who have suffered strokes, found that: very few had travelled by any public transportation during the past year. 9 percent had travelled by train. A further 30 percent said that they would like to travel by train. Among those who wished to travel but had not done so, 80-82 percent said that the obstacles were of a physical nature - getting to and from the train, getting onboard and getting off. 37 percent said there were cognitive obstacles too – problems booking, paying and finding their way around the station. 18 percent were frightened of travelling by train. Among those who had travelled by train, and told of their latest journey, physical obstacles were most apparent. The biggest difficulty was moving about on the train, but also moving around the station and getting on and off. Train travellers found it much more difficult than other travellers to access information at the station. 39 percent had had guides or assistants accompanying them on their latest train journey (less than half booked through the municipality). 6 percent had had difficulties booking an accompanying assistant. 99 percent were satisfied with their assistant.

**138.** Several associations, in connection with the writing of this report, also highlight many of the inadequacies mentioned in the questionnaire:

- It is often impossible to access important information, for example about delayed trains or traffic disturbances. There is a lack of information texts and those that exist are not always written distinctly with large letters and good contrast. Acoustics are often inadequate. If older transportation is used, accessible information about lines, destinations and station stops is often non-existent.
- Persons with asthma and allergies find it difficult travelling by the various forms of transportation. Serving nuts on air flights for example, or strong perfumes worn by staff and passengers. Many of these problems could be resolved by easy means.

### **139. COMMENT**

- The Special Transport Act is more than 30 years old. It is unacceptable that there are still so many deficiencies.

- Procurement of transportation must always include demands for accessible and usable means of transport that work all year round. All vehicles that are purchased, or adapted, must comply with technical standard, TSD.
- The national guidelines for accessible means of transport must be elaborated. Sweden should also work towards a broader use of the European Union's coming revision of the directives concerning TSD PRM (Transportation Systems Design for Persons with Reduced Mobility) and the inclusion of all those who are covered by Swedish disability policies.
- Failure to adhere to the existing regulatory framework must be "punished".
- Train companies should introduce spaces that are perfume free. Staff on the trains must be encouraged to stop using perfume and spreading the smell of tobacco.
- Sweden should work towards the development of ICAO's norms and recommendations and pay more attention to travellers with disabilities.
- Both public and private transport companies must be encouraged to inform travellers about accessibility. Examples are whether a train is accessible to wheelchair users, whether there are perfume free spaces, text information and whether the air-travel company serves nuts.

### **Penalties**

**140.** EG's Regulation number 1371 states, "Rail passenger services should benefit citizens in general. Consequently, persons with disabilities and persons with reduced mobility, whether caused by disability, age or any other factor, should have opportunities for rail travel comparable to those of other citizens." It goes on to say "Member States should lay down penalties applicable to infringements of this Regulation and ensure that these penalties are applied". The penalties, which might include the payment of compensation to the person in question, should be effective, proportionate and dissuasive.

**141.** Despite the Special Transport Act, the train company Veolia recently(2009) purchased trains that are not accessible for wheelchair users. It has been a year since the high-speed X2000 trains could accommodate wheelchair users because of problems with the lifts.

### **142. COMMENT**

- It is totally unacceptable that train companies buy vehicles that cannot be used by persons with reduced mobility or orientation capacity. Their behaviour is in conflict both with Swedish law and EU's Regulation. It is totally unacceptable that the high-speed X2000 trains have not been able to accommodate passengers in wheelchairs because of faulty lifts.
- The government of Sweden must more forcibly demand that the whole of the transport sector abides by existing legislation and, in accordance with EU's Regulation, lay down penalties for failure to consider passengers with disabilities.

### **Transportation coordination.**

**143.** The National Public Transport Agency estimates that it should be possible to accomplish satisfactory accessibility to common functions for all kinds of transportation such as information, ticket and booking systems and well functioning personal service and coordination between different parties within the transport sector. Whether the goal can be met in these respects is however primarily an organisational question that requires general transportation coordination. The National Transport Agency considers this may require compulsory measures or control instruments to achieve a sufficiently high quality arrangement.

### **144. COMMENT**

- A "whole journey" perspective must be applied so that a journey works from the beginning to the end for passengers with disabilities. Necessary control instruments must be identified and introduced.

- To make travel possible for individuals with, for example, cognitive disabilities, there must be clear and easily understood information, visual guidance, easily interpreted symbols at entrances, lifts etc. It is especially important, in the light of transportation coordination, that signs all look the same. Guidelines for information pertaining to the transport sector must be initiated.

## **Article 9 1.B Information and communication**

### **Regulatory framework**

**145.** According to the Regulation concerning government authorities' obligations towards persons with disabilities, authorities' information and activities must be accessible to persons with disabilities. There is no such obligation for municipalities. However, neither government nor municipality authorities are obliged to provide an individual with information in his or her chosen and usable media, for example Braille or digital.

**146.** The Administrative Procedure Act (Förvaltningslagen) says concerning authorities: section 8 "when an authority is dealing with someone who does not have a command of the Swedish language or who has a severe hearing impairment or speech impediment, the authority should use an interpreter when needed".

**147.** The Administrative Court Procedure Act (Förvaltningsprocesslagen) and The Swedish Code of Judicial Procedure (Rättegångsbalken) prescribe that interpreters should be used when necessary. These laws also include wording about translation into and from Braille. The Administrative Procedure Act has no such wording relating to Braille. The laws cover information and communication for the parties, but not accessibility of information for members of a jury.

**148.** The Electronic Communications Act (Lagen om elektronisk kommunikation) regulates delivery of electronic and communications services, among these telephone networks and computer communications. The law states that public services must always be accessible on equal terms all over the country. Sweden has made the decision to dismantle the fixed telephony network in rural areas. The mobile network that is suggested in its place means that electrohypersensitive persons who live in rural districts will be without a telephone. There is no legislation for the rest of society.

### **149. COMMENT**

- A regulatory framework must be initiated. It must be compulsory for municipalities to present their information to the public in a manner accessible to persons with disabilities.
- The regulations must be amended so that government authorities, courts and municipalities are obliged to provide the individual with information in the usable media of his or her choice.
- All public parties must be obliged to abide by the existing guidelines for websites and other electronic communications.
- Guidelines for accessible electronic communications must be initiated in those areas where they are still missing.
- Private parties that deliver goods and services to the public must be encouraged to present their information about the goods and services in a manner accessible to persons with disabilities.
- The Electronic Communications Act must be abided by so that electrohypersensitive persons, too, have access to the telephone network.

### **Statistical comparisons and research results**

**150.** Although government authorities are obliged to make their information accessible, this is not always actually the case. Statistics showing the accessibility of authorities' general information can be seen in Article 21 of this report. In the course of duty, as is seen in the investigation about victims of sexual crimes<sup>32</sup>, authorities do not have the knowledge about whether or not the regulations in the Administrative Procedure Act are abided by, or are sufficient.

**151.** A survey<sup>33</sup> carried out by The National Board of Health and Welfare at social services centres and healthcare centres, found that only one third of the social services centres had routines for booking sign language interpreters. There is information in Braille or digital talking books for persons with reading difficulties at only one in ten of the facilities. Technical equipment for persons who are hard of hearing are non-existent.

#### **152. COMMENT**

- All public parties must be obliged to introduce routines for making their information and communication accessible to persons with disabilities.
- Plans of action for introducing conversation-friendly sound environments should be compiled in all municipalities and county councils, likewise all authorities.

### **Article 9 2. A Monitoring**

**153.** There are several authorities that are tasked with monitoring and promulgating regulations regarding accessibility for persons with disabilities. The Swedish National Board of Housing, Building and Planning for example, is the administration that takes care of questions about built-up environments, physical planning and maintenance of buildings and residents' interests.

#### **154. COMMENT**

- The laws are restricted to apply only to persons with reduced mobility and orientation capacity, which means that monitoring all the regulations of existing legislation only covers these disabilities.
- The laws must be supplemented so that they regulate accessibility for all persons with disabilities. A consequence of this is that monitoring will include associated regulations and apply to all those who, in Sweden, are covered by the convention.
- Those responsible for monitoring must have the necessary knowledge of the wording of the convention, of the diversity of disabilities and of aspects related to disability.

### **Article 9 2. B Private Entities Facilities and Services**

**155.** The regulatory framework for accessibility in built-up environments applies to both private and public owners of buildings. Government authorities are obliged to provide accessible information and communication. There is no legislation for the rest of society. See comments under item 149.

#### **Inadequate accessibility as a grounds for discrimination**

**156.** Several articles in this report include statistics that show that the legislation concerning accessibility is not always abided by. The government, earlier on, chose not to take up the proposal of the Discrimination Committee that neglecting to take accessibility measures is to be viewed as discrimination. The government has implemented a new investigation, which also proposes that neglect to take measures for accessibility is to be viewed as discrimination. The Swedish Agency for Public Management, authorised by the government, has carried out a cost and benefit analysis of the investigation's proposals. The Agency concludes that banning discrimination in the form of inadequate accessibility could lead to significant costs for society.

#### **157. COMMENT**

- Introducing inadequate accessibility as grounds for discrimination entails new obligations for new parties in society. The one who is prevented from taking part on equal terms when laws are not abided by, is the individual with a disability. The possibility to influence one's own situation must be reinforced.
- The costs involved for reinforcing the discrimination law are probably mainly the result of previous neglect of existing legislation. The apprehensions that changing the law would involve unreasonable costs, we find strongly exaggerated. The adjustments will probably involve societal profit, as persons with disabilities can to a greater extent take part in working life and leisure activities thus becoming less dependent of public services.
- Neglect to take measures for accessibility stipulated in law must be judged as discrimination.

#### **The scope of protection against discrimination**

**158.** The current proposal states that the prohibition of discrimination through neglect to take measures for accessibility applies to all areas of society covered by the Discrimination Act. These areas are working life, labour market policy activities, education, membership of employer and employee organisations, health and medical care, social insurance, financial support for studies, national military service and buying goods or services, that is to say, largely economic and social rights. The European Convention of Human Rights and Fundamental Freedoms contains many civil and political rights. The European convention has been incorporated into Swedish law and can be referred to in a court of law.

#### **159. COMMENT**

- Because this law is also a law against discrimination, neglect to take measures for accessibility should apply also to its areas of implementation.

#### **Public procurement – a good tool**

**160.** The Swedish Public Procurement Act (Lagen om offentlig upphandling) stipulates that when public parties make technical specifications they must consider accessibility for persons with disabilities. The law applies to public procurement of building contracts, goods and services and building concessions. However, the law does not include regulations concerning the procurement of goods and services in connection with information and communication. Neither are there any demands for information about the accessibility of goods and services.

#### **161. COMMENT**

- All public procurement must include demands to insure that the procured goods and services are accessible to persons with disabilities. Existing national guidelines must be used when technical specifications are being drawn up.
- Sweden must push ahead the EU's standardisation work that aims to create universal guidelines for accessibility.
- Examples of specifications that have produced good results must be studied so that others can make use of them.
- A system for the following up of suppliers is needed.
- The Swedish Public Procurement Act must be supplemented with regulations concerning accessible information about the goods and services purchased by public parties, and regulations concerning procurement of services and systems in connection with information and communication. The law should also prescribe that suppliers provide information about the accessibility of goods and services.

#### **Conflicts of needs can be solved**

**162.** There is no support in Swedish law to guarantee that persons using service or guide dogs will be admitted into public places. It is often up to the individual businessperson to introduce

restrictions. A very common comment is that the guide dog cannot enter the premises because there might be persons with allergies inside.

#### **163. COMMENT**

- The fact that persons who use service and guide dogs can be refused entry into public places must be judged as discrimination, at least in those cases where there are no factual grounds for refusing entry. For example if another person is seriously allergic to furry animals and solutions for conflicting needs have been tried in the individual case.
- The parties of industry and economy must receive information about the agreement between The Swedish Association of the Visually Impaired and the Swedish Asthma and Allergy Association together with tips as to how conflicts of needs can be solved.
- The training for service and guide dog leaders must include showing consideration and finding solutions, so that problems for persons with serious allergies to furry animals are avoided.

### **Article 9 2.C Training on Accessibility Issues**

**164.** The disability associations feel that society often lacks the will to take measures to improve accessibility or to understand its consequences. There is inadequate knowledge about the regulations that dictate how premises, activities and information can be made accessible. Examples of professionals who need training are all those involved in planning and building, staff in the transport sector and in pre-schools and schools, social insurance offices, job centres and the healthcare sector.

Information campaigns about accessibility, usability and how important it is, for example, not to smell of perfume or tobacco are needed within the service sector.

#### **165. COMMENT**

- Training courses on accessibility and usability, the consequences of having a disability and existing regulations about accessibility must be introduced.
- Accessibility and usability for persons with disabilities must be included as subjects in training for building environments, means of transport, information and communication.
- Specialist training is needed within diverse accessibility areas (for example acoustic professionals).
- Campaigns to raise public consciousness and knowledge about the significance of accessibility must be carried out.
- The positive outcomes of a society for all must be emphasised more clearly in public discourse.

### **Article 9 2.D Signage in Braille and Easy to Read Forms**

**166.** The Swedish National Board of Housing, Building and Planning's regulations for easily remedied obstacles include, among other things, advice about contrast marking of level differences and the use of Braille. A survey<sup>34</sup> of social services offices and healthcare centres found that not even half of their activities have assistance for persons who are partially sighted, in the form of handrails and contrast marking in lobbies, or Braille signage and synthetic speech in lifts. Only one in ten of the activities had information in Braille or in digital format, or talking books for persons with reading difficulties.

**167.** Handisam's 2010 survey of authorities reported that 50 percent of those who responded had glass doors marked at eye level, 47 percent had tactile marking of buttons in lifts, 27 percent had a voice in lifts telling which floor and 40 percent had contrast marking on all their stairways.

#### **168. COMMENT**

- The questionnaire shows that not even half of the government authorities, with a clear responsibility to make their premises accessible for persons with disabilities, adhere to the regulations.

### **Article 9 2.E Assistance and Intermediaries**

**169.** The EU Regulation 1371 concerning rail passengers' rights and obligations took effect in December 2009. It gives individuals the possibility to book an accompanying person for a train journey. Six months on, there are still huge inadequacies. There is no common booking system for accompanying persons and portable ramps, for example. This is the case even when tickets for journeys with different companies can be booked from the same place. The system's new limitations have led to accompanying persons not being allowed to board trains with the passenger. Assistance on board the trains, supposed to be provided by the staff, works badly or not at all. It is especially difficult to find satisfactory assistance when changing to a different rail company. Even if assistance is needed on the very same station, one assistant goes off duty, and another one comes on. These limitations make a journey very risky and insecure.

**170.** In Sweden there is often a lack of targeted resources for the use of sign- language interpreters. The lack of targeted resources for interpreters limits the individual's access to interpreters and also public opportunity to promote sign- language as prescribed in the Language Act (see article 21).

#### **171. COMMENT**

- The restrictions to assistance when travelling must be removed and a perspective of "the whole journey" applied so that persons with disabilities may travel on equal terms with others. Individuals must receive satisfactory assistance even when changing rail company.
- Supplementary regulations are needed so that bus companies are obliged to provide assistance. Many bus companies do not have this service, which makes it very hard for persons with disabilities to travel.
- County councils are obliged by law to provide sign language, deaf-blind and written interpretation. However, it has proved insufficient. A special researcher (Dir.2010:87) will map and analyse how the current regulation works in different areas of society in connection with funding, organisation and monitoring of interpreters for the childhood deaf, deaf adults, persons who are hard of hearing and the deaf-blind. We hope that the survey will lead to society taking full responsibility for interpreter services.

### **Article 9 2.F Alternative Solutions**

**172.** Societies are moving towards a time when individuals themselves need to collect information and communicate digitally. This applies to information from authorities, municipalities and from private parties. To enable persons with disabilities to partake of the information the following is necessary:

- The information must be accessible for persons with disabilities (see article 9, item 2g).
- Individuals must have access to a usable computer or other means of communication, including necessary technical aids. As can be seen in article 28, economy is often more of a problem for persons who are covered by the Act concerning Support and Service for Persons with certain Functional Impairments (LSS), than it is for others. Because of their economic situation, they do not have similar access to their own computer or mobile telephone<sup>35</sup>. Difficulties for persons with hyperelectrosensitivity must be acknowledged. Article 21 notes the difficulties persons

with disabilities experience in accessing public information in alternative formats, Braille is one of them. There are several alternative services, special transport for the partially sighted is one of them, where a paper can be faxed and the text read out over the telephone; but there is no comprehensive picture of needs, supply and demand.

#### **173. COMMENT**

- Developing the means of making information and communication accessible is necessary. Methods that have been tried and tested and found to be sound must be put to use. For example the "pocket interpreter", which makes communication accessible to the deaf and the hard of hearing, should be on offer for those who need it.
- Ways of improving accessibility to warning texts, tables of content and other information on products and in manuals, must be found. There is a need of guidelines for bar-code information, for example.
- National guidelines for the allocation of technical aides are needed, see further article 26, item 467-470.

### **Article 9 2.G Accessible Information and Communications Technologies**

**174.** Handisam, The Swedish Agency for Disability Policy Coordination, has produced a plan of action for e-inclusion<sup>36</sup>. It states that e-inclusion means that goods and services, and systems that are based on Information and Communication Technology (ICT), must be designed correctly from the start, taking into consideration human diversity and that usability and accessibility are quality goals in the developing process. Much effort is needed from different sectors of society to safeguard the accessibility and use of ICT. The report defines 12 efforts needed in order to live up to the vision that all people should be able to use ICT. One of these is to initiate and coordinate statistical groundwork as a point from which to monitor development. In the autumn of 2010, the government commissioned Handisam to identify such indicators and to make proposals for a structure to monitor e-inclusion.

#### **175. COMMENT**

- Public services must be designed so that they can be used by the broadest possible sector of users, regardless of age, sex, disability and cultural or ethnic background.
- Measures must be speedily taken to ensure that digital society is designed and developed without creating new obstacles for participation.
- There must be a dialogue with disability associations about which measures should be prioritised.
- The proposed efforts must be implemented.

### **Article 9 2.H Universally Designed ICT**

**176.** The Electronic Communications Act applies to electronic communications networks and communications services with associated facilities and services together with other radio use. It covers the technical infrastructure but not the content that is being transferred across electronic communications networks assisted by electronic communications services.

#### **177. COMMENT**

Supplementary regulations concerning accessibility to electronic communications must be initiated. Many obstacles need bridging, for example:

- The Swedish Stuttering Association highlights the need of alternatives to voice steering on the telephone
- The alerting number 112 works by text telephone, but to raise an alarm using a text message, it is necessary to register your mobile phone number. Persons who are hard of hearing, deaf

persons and the deaf-blind who have not registered their mobile number may also need to alert by text message.

- Broadband operators offer deals where the equipment cannot be used with picture phones (SIP-compatible).
- Disability associations must be involved in the work to compile regulations for electronic communications services to ensure that diverse disability aspects are heeded.
- We would also like to stress the importance of comprehensible information to consumers about electronic communications. The conditions attached to various products and services, and when changing operator, are complicated. There is a need to analyse the costs that different consumer groups have for electronic communications to see if persons with disabilities costs are greater than others, and if this is the case, why.

**178.** The Disability Movement's recommendations, see annex 2

## **Article 10 Right to life**

**179.** The Swedish disability movement does not have any points of view on current legislation in Sweden that concerns this article. There are however some shortcomings in the social system that contribute to people nevertheless being deprived of life. In the alternative report on civil and political rights, article 6, there is information about: death after injuries and accidents that could have been prevented; deficiencies within healthcare and medical treatment that lead to death, and information about the occurrence of lethal violence. The report shows that persons with disabilities are an especially vulnerable group in these contexts. There are however no comprehensive statistics about the reasons why individuals with disabilities have died.

### **180. COMMENT**

- There is a need for research into the reasons and causes of why girls, boys, women and men have died.
- Many of the reasons described that lead to death can be dealt with and failure to take measures is inconsistent with article 10.
- The authorities responsible must take measures to reduce the risk of accidents that can lead to death. Many lethal accidents can be prevented by using simple measures. For example employing a municipal caretaker to help the elderly with everyday chores, changing bulbs, putting up curtains or other situations where there is a substantial risk that elderly people might harm themselves.
- The Protection against Accidents Act (described in article 11), must be complied with.
- Place of residence or doctors' negative attitudes should not influence the chances of survival. All people, regardless of functional capacity, age, gender, and place of residence or living conditions must receive equal care.
- The use of national guidelines and a quality register must be expanded so that causes of malpractice and mortality can be evaluated. National guidelines provide increased uniformity and prevent malpractice that can lead to death. Quality registers provide medical staff, politicians and decision makers with the opportunity to evaluate and follow up decisions.
- Every person who is killed is one person too many. It is good that the number of children who die on account of violence is reducing, but society must demand zero tolerance. Further measures must be taken to reduce the number of children and adults who die each year as a result of lethal violence.

### **Mortality among mentally ill persons**

**181.** A recent report<sup>37</sup> from the National Board of Health and Welfare notes high mortality due to somatic diseases among patients who were treated for mental health reasons. Deaths caused by strokes or coronary thromboses were also higher among persons who were being treated for mental health reasons, than for those with no such diagnosis. A similar increase of survival after thrombosis and strokes found in the population as a whole over the past five years, is not seen among persons with mental health diagnoses. The survey shows that young women are over represented and that they have substantially increased their use of hospital care over the past ten years. The same applies to young men. The increased need for medical care among young people does not correspond to that of other age groups. On the contrary, here the need seems to have decreased. Death by suicide is decreasing in all age groups, except the youngest. The report finds that cases of hospital care of self-harm behaviour have increased over recent years. A report from the Swedish National Institute of Public Health 2009<sup>38</sup> notes that the increase is found primarily among young women. The National Board of Health and Welfare states in the above-mentioned report that there is a need for coordinated efforts at national, regional and local levels to cater for the mental health of the elderly.

### **182. COMMENT**

- County councils must forthwith take necessary measures to reduce mortality among patients with mental health illness. Attention must be given, for example, to somatic disease, together with various possible mechanisms that effect mortality.
- Strategies to reduce mental health illness and to promote mental health among the young must be developed.
- Shared strategies must be devised for the responsibility of the mental ill health of the elderly.

### **Lethal violence within mental health care**

**183.** There have been two tragic deaths within mental health care reported by the media. One took place in Karlstad where a person was suffocated to death by carers. The person in question was lain face down and the carers pressed the person's arms downwards where their body weight caused the person's breathing and circulation to collapse. The violence led to immediate death. The other case is from Södertälje. Again the patient was thrown face down onto the floor with arms twisted backwards and upwards. This time too, according to investigations, the carers pressed their body weight down onto the patient causing death. The National Board of Health and Welfare, the authority responsible for the supervision of mental health care, however, has no plans to ban the dangerous restraint holds. This was stated by the National Board of Health and Welfare's supervisory doctor in an interview on the Swedish Radio's daily news report about the death in Karlstad.

### **184. COMMENT**

- The National Board of Health and Welfare must forthwith issue guidelines for emergency care in violent situations that occur within the mental healthcare system!

### **Deportation of the seriously ill**

**185.** The disability movement 's organisations wish to highlight the cases where immigrants with disabilities and serious diseases are not granted asylum in Sweden or are to be deported, despite the individual's lack of access to adequate treatment in his or her home country. According to The Aliens Act (Utlänningslagen), disability or serious diseases are not bases for granting permission to stay.

There is a possibility to apply for a residence permit on the grounds of "particularly distressing circumstances" but the law and praxis are very restrictive. The fact that there is any medical care at all in a home country is sufficient to refuse permission to stay in Sweden. It is not taken into consideration whether or not a person can gain access to care.

**186.** An example of this is the case of Shwan Fatah, who was deported from Hedemora to Iraq in 2008. Shwan was paralysed from the waist down and in need of drugs that were not accessible in her country. Her death in 2010 was due to complications in connection with her illness.

**187. COMMENT**

- Deportations of this nature are a serious crime against human rights because the actions may lead to a person's death. To die of aids without access to painkillers can also be classified as torture.
- The Aliens Act must be reviewed so that persons with serious diseases or disabilities cannot be deported if deportation could lead to death.

**188.** The Disability Movement's recommendations, see annex 2

## **Article 11 Situations of risk and humanitarian emergencies**

### **Regulatory framework**

**189.** The public sector's responsibilities during war or the threat of war are found in a law laying down duties for municipalities, administrative authorities and courts during war or the threat of war. The law has no special mention of persons with disabilities.

**190.** Municipalities and county councils at the start of each new term of office, according to the Act on Municipal and County Council Measures Prior to and during Extraordinary Events in Peacetime and during Periods of Heightened Alert (LEH 2006:544), should decide on a plan about how to deal with extraordinary situations. Nothing particular is said in the law or its regulations about persons with disabilities.

**191.** The Civil Protection Act describes among other things the task of the Swedish Civil Contingence Agency (MSB) to enhance and support the rescue operations undertaken by state or municipality in the case of emergencies or imminent danger of emergencies and to prevent and limit damage to individuals, property and the environment. The law also regulates written information in connection with fire protection. The all round advice about fire alerts in homes and fire protection in hotels, inns, youth hostels and suchlike buildings also includes special consideration towards persons with disabilities.

**192.** The regulatory framework concerning emergency exits does not include demands of accessibility for persons with disabilities. See further under article 9 item 124.

**193. COMMENT**

- The laws encompass persons with disabilities who shall thus receive equal protection in situations of risk and humanitarian emergencies. In order to reach persons with disabilities at rescue operations, knowledge about their preconditions and the ability to identify and deal with persons with disabilities in emergency situations is of the utmost importance. Alternative methods of alerting rescue teams are equally important.
- The county administrative boards as coordinating bodies between local parties such as municipalities, county councils and business should be charged with guaranteeing that all rescue operations also reach persons with disabilities. This may involve requiring each party to supplement their plans if the perspective of disability is lacking.
- Accessible evacuation means that it must always be accessible for persons with disabilities. The emergency exits for example must be made physically accessible and when emergency strikes, the way out must always be marked with light, sound and cognitive/visual signals.

- Inadequacies and shortcomings of the regulatory framework that lead to persons with disabilities not receiving necessary support must be identified and rectified.

### **Statistical comparisons and research results**

**194.** The planning and implementation of a rescue operation is largely a matter for the municipalities. The Civil Contingence Agency's annual survey<sup>39</sup> notes that barely 70% of the municipalities have implemented a comprehensive risk and vulnerability analysis in accordance with LEH (most common within care of the elderly and domestic water supply). Just 150 of the 282 municipalities that responded have implemented a risk and vulnerability analysis for disabilities. The survey gives only a quantitative picture of municipalities' preparedness for crises. It does not measure the quality of the diverse efforts. It is thus not possible to judge the extent that municipalities take note of disabilities in their plans.

**195.** A question in MSB's survey is whether municipalities have a local advisory group for management of a crisis, or the equivalent. Only 121 municipalities had such groups. Many municipalities however said that they were in the process of starting crisis groups or that they are in touch with other networks that prove more suitable for the purpose. Most municipalities collaborate with the police, the county council and the county administrative board. 180 of the 282 municipalities that responded say that they cooperate with voluntary organisations, for example the Civil Defence League and the Red Cross.

### **196. COMMENT**

- Indicators to gauge the quality of municipalities' risk and vulnerability analyses and highlighting of persons with disabilities in their crisis management plans must be introduced.
- MSB's review does not show to what extent there is collaboration with various disability organisations. The local branches are significant channels for reaching persons with disabilities. It is therefore important that the collaboration processes between the disability movement and municipalities in situations of risk and humanitarian emergencies is improved.

### **Training**

**197.** The task of the MSB is to enhance and support societal capacities for preparedness for and prevention of emergencies and crises. The agency works closely together with SHIA, an umbrella organisation for the disability movement that works with international growth. SHIA has taken part in several training courses for rescue personnel in order to include the perspective of disabilities through better awareness and knowledge. Their collaboration aims at focusing on persons with disabilities in emergencies, both in Sweden and when Sweden sends rescue teams to other countries.

### **198. COMMENT**

- The disability movement welcomes collaboration with MSB and wishes it to evolve. The training courses should however be made available to more parties.

### **Developing practical solutions**

**199.** The emergency number 112 works using text telephony. Individuals can also alert through videophone, but it is not open round the clock. The pilot scheme, alerting 112 by text message<sup>40</sup>, is a joint development project involving SOS Alarm and The Swedish Post and Telecom Agency (PTS), where the deaf, the hard of hearing and persons with speech difficulties can contact SOS Alarm using text messages. In an emergency the SOS operator using text messages will be able to ask complementary questions needed so that help is sent to the right place. To access this service it is necessary to register with SOS Alarm's website.

#### **200. COMMENT**

- The pilot scheme, alerting 112 by text message should be permanented. Persons who are deaf or hard of hearing and deaf-blind who have not registered their mobile phone number must also be able to alert using text messages.
- The videophone service SOS Alarm must be available for contact round the clock.
- More practical solutions must be developed, experience gained through pilot schemes must be used and successful results made permanent.

#### **Accessible emergency exits**

**201.** It is very unclear whether diverse societal players take note of accessible emergency exits for persons with disabilities.

Three of four healthcare centres do take note of persons with disabilities in their systematic work for fire protection<sup>41</sup>.

Handisam's questionnaire does not ask questions about dealing with emergencies or accessibility for evacuation.

#### **202. COMMENT**

- A survey of all public parties' preparation for the evacuation of persons with disabilities and accessibility of rescue exits must be carried out. A survey of accessibility of all public premises must also be carried out.

**203.** The Disability Movement's recommendations, see annex 2

## **Article 12 Equal Recognition before the Law**

### **Article 12. 1 and 2 Legal entity, legal capacity and legal capacity to act**

**204.** The point of departure in Sweden is that all persons are legal entities. All legal entities have legal capacity, that is to say they can be bearers of both rights and responsibilities. On the other hand, not all persons have legal capacity to act, that is to say capacity to undertake a legal act, for example enter into an agreement. A child cannot go to the bank alone and withdraw money from an account that is in the child's name. As a legal entity the child can have an account, but does not have his or her own legal capacity to act. Full legal capacity to act is only acquired on reaching majority, that is to say at the age of 18. Declaration of incapacity is now completely abolished in Sweden. Help and protection for those who would previously have fallen into this category can instead be achieved in another way, for example by authorising an administrator or a trustee. See items 206-207.

#### **Acting under mental illness**

**205.** The Act on the Effect of Agreements Entered into under the Effect of Mental Disturbance (1924:323) concerns legal acts undertaken by persons who are acting under mental illness. The act states that such agreements are not valid. This does not mean that all agreements entered into by a person with a mental disability are invalid. Somewhat simplified, one can say that the agreements that are invalid are those that the private individuals would not have entered into if they had been "in full possession of all their faculties". The intention of the act is primarily to protect the "sick", however to some extent also the person with whom the sick individual has entered into a legal act. For further information see the Swedish disability movement's alternative report, article 16 concerning civil and political rights.

### **Article 12. 3 and 4 Access to support**

**206.** The provisions in the Childrens and Parents Code, concerning administrators and trustees, give a person in need of support in order to exercise his or her legal capacity, satisfactory support

and protection. According to the act an administrator shall accommodate the needs of the individual in every special instance. There are however difficulties in connection with the current system of administrators. It tends to become more or less “permanent”. This applies especially to those with learning disabilities. Before a person can be allotted an administrator a medical report is required. Once such a report has been written it is difficult to revoke the administrator as learning difficulties, from a medical point of view, do not get better. Because of a medical report, a person with intellectual disabilities risks having an administrator longer than necessary. In real life this means that persons cannot enjoy their legal capacity as prescribed in the convention.

#### **207. COMMENT**

- The law must be quite clear that a trustee or some other less intrusive assistance shall replace an administrator when an individual is no longer in need of an administrator.
- The act must emphasise a point in time for reassessment.
- Trustees and administrators have, in general, insufficient knowledge about mental and intellectual disabilities and their consequences. The board of chief guardians should therefore be authorised to safeguard that trustees and administrators have the necessary knowledge to carry out their tasks.
- Municipalities’ routines for appointing trustees and administrators sometimes have shortcomings. Likewise the way in which they define the duties. An individual’s opportunity to influence the work and who carries it out must be reinforced.

**208.** Several associations highlight cases where decision makers, executive officials and personnel of the courts do not apply or interpret the law on an equal basis with others with reference to persons with disabilities. For further information about these extremely crucial instances, see articles 13 and 14.

**209.** The Disability Movement’s recommendations, see annex 2

## **Article 13 Access to Justice**

### **Article 13 1 Effective access to justice**

#### **Regulatory framework**

**210.** The laws and regulations of the judicial process apply to persons with disabilities. As the Swedish disability movement has no points of view on these procedures, the general framework is not described here.

**211.** Accessibility to the courts and police premises is laid down in the Regulation for Public Responsibility for Disability, see article 9.

**212.** The Swedish Code of Judicial Procedure’s regulations (1942:740) (see chapter 12, section 22) concerning counsel ensure an individual the right to a legal assistant. The assistant can give legal advice and by power of attorney represent a person in court.

**213.** The Administrative Procedure Act (1986:223) stipulates that “When an authority is dealing with someone who does not have a command of the Swedish language or who has a severe hearing impairment or speech impediment, the authority should use an interpreter when needed.”

**214.** The Administrative Court Procedure Act (1971:291) and The Code of Judicial Procedure stipulate that an interpreter should be used when needed. The laws also include mentions of translations to and from Braille. The Administrative Procedure Act has no such wording

concerning Braille. The laws cover information and communications for the parties, but do not regulate accessibility for jury members. See comments and recommendations in article 9.

### **Statistical comparisons and research results**

#### *The organisation's experiences*

**215.** In connection with the writing of this report, several associations have noted that, generally speaking, it is difficult for persons with disabilities to claim their rights and needs from “the apparatus of society”. This includes administrative authorities’ handling of matters and all the cases that have been appealed and ended up in court. The shortcomings in court proceedings, highlighted in the Swedish disability movement’s alternative report on ICCPR, still remain. Article 14, page 79, of the alternative report gives facts and illustrative examples, and in article 9, page 56, there is information about court decisions concerning deprivation of liberty. Below some supplementary information concerning crime victims with disabilities.

#### **216. COMMENT**

- Adequate knowledge of what different disabilities can entail, diversity among persons with disabilities and respect for the consequences of different disabilities must permeate the entire judicial process. Administrative courts, ordinary courts and special tribunals must all have adequate knowledge.
- If necessary it must always be possible to acquire special support and accessible information and communications in connection with police interviews, investigations and court trials. Whether or not there is a need shall be decided by the individual.
- Judges who preside over cases concerning compulsory care and other persons involved, such as jury members, experts and public counsels, must have necessary knowledge about different mental disabilities so that these can be put in relation to the individual’s circumstances and overall life situation.

### **Crime victims with disabilities**

#### *Invisible crime victims*

**217.** According to a survey<sup>42</sup> from the National Council for Crime Prevention, violence against persons with disabilities does not feature in crime statistics. The survey finds that vulnerable people are often unable to voice their opinions in a way that works for them. The researchers note that in order to give persons with disabilities increased accessibility to the judicial process and equality before the law, the violence committed against this type of victim must be visible in crime reports. The National Police Board confirms that there are no special routines for how victims with disabilities are received or how they are made noticeable in police reports.

#### *Young crime victims with disabilities*

**218.** Researcher Ann-Christin Cederborg of the University of Linköping and Karolinska Institute, has studied children with disabilities as victims of crime. She found that when the legal system judges credibility it does so on the grounds that all people have the same ability to relate coherently and in detail. This means that the law makes no difference between persons with disabilities and others when judging credibility. An important credibility principle in Swedish legal procedure is that narratives are coherent, detailed and not contradictive. Cederborg notes that it may be especially difficult for children with disabilities to live up to these criteria, and also that there is little attention paid to the way in which the police present the preconditions for the child’s narrative. If the interview techniques used by the police include many leading questions and repetition of questions, there is an increased risk that children with intellectual difficulties will not speak coherently and in detail.

#### *Women with disabilities*

**219.** At a presentation<sup>43</sup> of the association of women attorneys it was noted, that women with disabilities often have greater difficulties convicting a person who has committed a crime of violence against them, because the crimes are often more difficult to prove. The presentation told that women with disabilities who are exposed to violence have greater difficulties in pursuing cases through the courts and in being believed during an investigation and in court.

**220.** Handu's survey<sup>44</sup> from 2007 shows, in connection with crimes against persons with disabilities, that the exposed person does not always receive the assistance he or she is entitled to and needs, or access to a support person he or she can trust. This is especially true when the case concerns violence against women.

**221. COMMENT**

- Progress has been made by different parties of society in implementing training courses, methods and checklists that take note of disabilities.
- Current methods to establish awareness and treatment of different disabilities within the entire legal system must be evaluated coordinated and followed up so that the treatment of girls, boys, women and men with disabilities improves in all legal contexts.
- All agencies related to the judicial process must be charged with introducing new routines that include awareness of disabilities. The personnel in question must always ask whether persons with disabilities need special support and/or adaptation before and during the legal proceedings.

**Discrepancies of legal practice**

**222.** Chapter 14 of the Swedish disability movement's alternative report notes discrepancies in how courts interpret and apply the law. This happens especially to persons with mental, neuropsychiatric and intellectual disabilities. A review of lower court judgements from 2009 also found that there are many ambiguities and discrepancies that are difficult to explain when the law is applied to a person with HIV who is prosecuted for a crime deriving from infection. Researchers state that to ensure that these people enjoy equal rights in the judicial process, measures of some kind must be taken.<sup>45</sup>

**223. COMMENT**

- Measures must be taken to guarantee that equal rights in the judicial process are identified and implemented.

**Interpretation that conforms to the convention**

**224.** The UN's convention on human rights has not been "transformed" into Swedish law. Interpretation that conforms to the convention is applied. This means that laws are interpreted so that we live up to Sweden's International Agreements. The Swedish National Courts Administration's (Domstolsverket) strategic focus for the period 2010-2020 includes overall visions and goals, and suggestions as to how they can be reached. The Swedish disability movement can confirm however that The National Courts Administration's strategy does not include any mention of interpretation of Swedish law that conforms to convention rights.

**225. COMMENT**

If there is to be a breakthrough for the rights of persons with disabilities and other international documents into the Swedish legal system, the demand for interpretation that conforms to the convention must be clearly emphasised. The National Courts Administration's strategic focus can, for example, be supplemented with the following goals:

- All judicial operations shall reflect Sweden's International Agreements.
- Measures to ensure that interpretation conforms to the convention must be identified and implemented. Examples are methods that coherently emphasise interpretation that conforms to the rights of the convention in all reasoning and all judgements.

### **Accessibility to the courts**

**226.** The National Courts Administration has produced a plan of action concerning accessibility to judicial operations and Sweden's courts for the period 2008-2010. The plan covers premises, communications and information, activities and personnel matters. There is no evaluation of the plan of action at hand. Neither is there any comprehensive statistic material covering physical accessibility in the courts. The questionnaire authorised by Handisam in 2010 however, found that only half of the courts have compiled a plan of action for their work for accessibility. There had been no great change between 2008 (54 percent) and 2010 (55 percent). Just over two thirds of the courts (65 percent) had appointed a coordinator for 2008. In 2010 the percentage had dropped to 45 percent.

There are still substantial shortcomings of accessibility to information and communications. Access to technical aids for the deaf and hard of hearing and/or sign-language interpreters is inadequate. The magazine Auris has reported<sup>46</sup> on a case where individuals were unable to hear the judge's decisions due to lack of technical equipment in the courtroom.

The National Courts Administration's strategy lacks entirely direct mention of support for the individual who has special needs and accessibility to the courts and to judicial operations for persons with disabilities.

#### **227. COMMENT**

- All courts must be charged with speeding up their work to make their premises, activities and information accessible to persons with disabilities.

### **Public funding – legal aid**

**228.** To enable persons to pursue cases in courts, some may receive legal aid. The provisions of The Legal Aid Act, part of social protective legislation, regulates this and aims to help persons who cannot find legal assistance anywhere else. Legal aid covers the costs of a lawyer or some equivalent person. The costs for statements of evidence can also be met. Legal protection is usually included in home insurance. More or less the only cost at a trial for persons with home insurance is the excess. Under certain circumstances people may receive state legal aid if the legal protection included in their home insurance does not cover the dispute. Legal protection normally covers precise disputes in general courts. It does not however usually cover disputes concerning labour law, straightforward divorce or administrative cases. For example infringement of private life such as deprivation of liberty and decisions concerning an administrator/trustee are administrative cases and, as such, not included in legal protection. This can lead to people not being able to afford to take their cases to court.

#### **229. COMMENT**

- The area covered by legal aid should be extended to include social security cases and cases involving social legislation.

### **Article 13 2 Training**

**230.** The Swedish Police and others have over the past few years taken part in training courses about how to interview children and adults with disabilities.

In Sweden, only the deaf automatically receive help and are noted in police documents as having a disability. The federation points out, though, that knowledge about the deaf and hard of hearing and of sign language is very inadequate in the judiciary and the police force. Sign-language interpreters must be more frequently engaged to ensure that translations to and from sign language and spoken Swedish are correct.

### **231. COMMENT**

- The training courses that have taken place must be evaluated and followed up. The judiciary and the police force must invite the disability movement to take part in the work to organise opportunities for information and training of personnel. The training should focus on questions of treatment and of the special needs that persons with disabilities may have and how these needs can be practically managed during court proceedings.

**232.** The Disability Movement's recommendations, see annex 2

## **Article 14 Liberty and Security of Person**

### **Regulatory framework**

**233.** According to Swedish law, persons can be deprived of their freedom on account of: Having committed a crime or suspected of having committed a crime. – Compulsory care. – Risk of spreading an illness that is a danger to the public. – Detention of foreigners (in custody – usually in connection with a person having received a decision on refusal of entry or deportation and the Migration Board has reason to believe that a person will go into hiding. An asylum seeker can be held in custody if his or her identity is unclear).

### **Deprivation of liberty on account of a crime**

**234.** A description of the regulatory framework in connection with deprivation of liberty on account of crime or the suspicion of crime can be found in article 9 of the Swedish disability movement's alternative report on civil and political rights. Also how lack of knowledge about the treatment and interrogation of persons with mental, neuro psychiatric and intellectual disabilities can lead to persons confessing to crimes they have not committed. People with disabilities must receive information on why they have been deprived of their liberty in a language they understand so that they can take in the information.

### **235. COMMENT**

- All people regardless of ability must take responsibility for their actions. The sanctions system must however take into account people's diverse abilities and need of care.
- Against a background of the current problems for persons with intellectual and mental disabilities in the "normal" system of sanctions, the recommendations from the Committee of Mental Responsibility concerning closed accommodation for certain offenders must be implemented forthwith. It is of great importance however that this type of accommodation is modelled on the principles of LSS in order to avoid a gradual retrogression to special hospitals.
- All personnel within the police and the judiciary must have adequate knowledge about treatment and interrogation of persons with mental, neuropsychiatric and intellectual disabilities.

### **Compulsory care**

**236.** Information about LVU and LVM, laws covering the care of young criminals, can be found in article 9 of the alternative report on civil and political rights.

**237.** Since the 1970s Sweden has undertaken to de-institutionalise hospitals for the mentally ill and many have been closed down. In order to provide support for those who would previously have become patients at these hospitals, psychiatric reform work started in Sweden in 1995. The outcome was joint responsibility for county councils and municipalities to provide adequate care for persons with mental disabilities.

**238.** According to the law on Psychiatric Compulsory Care, persons with severe psychiatric disorders can be deprived of their freedom and taken into care. It must however be necessary with regard to a person's psychiatric condition and personal circumstances and that he or she needs qualified psychiatric hospital care around the clock. For example a person's life or health must be at risk or other people's security. The patient, him or herself, must be opposed to this kind of care.

**239.** In 2009, a new form was introduced to psychiatric compulsory care – non-institutional compulsory care. The prerequisites for being admitted to psychiatric compulsory care have not changed which means that compulsory care always starts in hospital. The new form of care is designed to accommodate patients' individual needs of care when they leave hospital. The head medical director makes the application when he or she considers that a patient should be cared for in this manner. The general administrative court makes the decision. An application for non-institutional compulsory care must include a comprehensive care plan, detailing among other things the patient's need of various activities provided by social and healthcare services, and the county council or municipality or other unit that is responsible for the planned activities. A municipality decision concerning a patient's needs must also be attached to the application. When applying for an extension of non-institutional psychiatric care a follow-up of the care plan is needed. A similar form of care has been introduced into forensic psychiatric care.

**240.** In the alternative report on civil and political rights, the importance of impartiality and independence of judges presiding over cases concerning compulsory care is stressed. The research referred to, finds that it is very rare for a court to judge contrary to a doctor's opinion. The researchers point out that a court often takes for granted what it is there to form an opinion about, namely a patient's mental illness. "It is a Moment 22 situation; if a patient accepts that she is ill, then she is ill, if she says the opposite it is interpreted as a lack of insight into her condition". More recent studies in this area are not available.

#### **241. COMMENT**

- The criteria for psychiatric compulsory care are interpreted differently depending on which clinic and where in the country the decision is made. Supervision of practice must be put into place and work to follow up how care professionals and courts live up to laws and regulations.
- Judges that preside over cases concerning compulsory care as well as other players involved at the courts – lay judges, experts and public counsel – must have the necessary knowledge about different mental disabilities so that these can be put in relation to the individual's circumstances and overall living situation.
- Care plans must always be written in collaboration with the person involved.
- The occurrence of double diagnoses must be attended to and casual connections investigated so that individuals receive adequate treatment in connection with compulsory care. This is with the aim of reducing the risk of being detained again, and to increase the possibilities for reassimilation into society.
- With mental illness and addiction, so-called double diagnoses, the responsibility for medical treatment and rehabilitation lies with the head of health care services. Treatment must take place simultaneously for both conditions. It is also important that there is subsequent cooperation between municipalities and county councils so that there is no gap in the care – welfare – rehabilitation chain.

#### **Compulsory isolation**

**242.** According to the Law Against Infectious Diseases, a person who has an infectious disease that is dangerous to the public is isolated if

1. Circumstances clearly indicate that an individual is not prepared, or able, to voluntarily undergo the treatment necessary to prevent or as far as possible minimise the risk of spreading infection or
2. There is every reason to believe that an individual will not abide by the rules that have been decided.

In fact, practically all of those who have been condemned to compulsory isolation have been persons with HIV. Most of the cases of isolation are persons who are addicted to drugs and/or have psychiatric problems which could lead to them spreading disease.

When crimes are committed, for example consciously spreading disease, it is the criminal code's provisions that are applied. Sweden has been criticised twice by the European Court of Justice because compulsory isolation is inconsistent with the<sup>47</sup> European Convention. Despite this, Sweden has not yet changed the wording of the law.

#### **243. COMMENT**

- The risk, due to the current provisions of the Law Against Infectious Diseases, that people are deprived of their freedom must be judged inconsistent with article 14.
- Care, rehabilitation and support must be given to people instead of compulsory isolation, as is the case today.

### **Article 14 1 B Arbitrary deprivation of liberty**

#### **Statistical comparisons and research results**

**244.** As shown in article 9 of the alternative report, many people, quite unnecessarily, are deprived of their freedom because of inadequate care and support. Research<sup>48</sup> from 2010 finds that about 40 percent of men imprisoned for long-term sentences, suffer from previously unknown and untreated ADHD, although they have had significant problems since childhood. The researchers pointed out that the disabilities of prison inmates with ADHD are greater and have more distinct symptoms than corresponding ADHD groups in psychiatric care in society. Research shows that those in the prison group have grown up without adequate treatment and support for their disability. Although most of the inmates needed extra support at school and contact with healthcare services while growing up, very few have been diagnosed with ADHD or other neuropsychiatric disorders, and even fewer have received treatment. Addiction is more common in connection with untreated ADHD; in the current survey all the inmates with diagnoses had had addiction problems. The researchers also noted an overrepresentation of other treatment-heavy psychiatric disorders in the ADHD group. Almost half of the group were regularly taking medicine for more than one psychiatric disorder. Almost 25 percent, when examined, also received a diagnosis along the autism spectrum. And they qualified for the criteria of personality disorders of the anti-social type. Psychopathy was rare.

#### **245. COMMENT**

- People with mental and neuropsychiatric disabilities must have access to adequate preventive care, habilitation and rehabilitation so that people are not deprived of their freedom to the extent they are today.
- Forensic psychiatry, general psychiatry, prison services, care of drug addicts and municipalities must take vigorous measures to improve coordination, rehabilitation. quality work and raised competence around persons with mental disabilities.

#### **Children**

**246.** Over the past few years, the media have reported on children who have been deprived of their freedom. The Swedish Radio's Eko-news on February 12<sup>th</sup> 2010, reported how children at young people's homes were punished by being illegally locked up in isolation.<sup>49</sup> According to a survey,

The National Board of Institutional Care, (SIS), had looked into all the cases of isolation that had occurred over the past year, but the media survey showed that SIS had not, in any of the cases, been in touch with the isolated children.

### **Article 14 2 Treatment of people deprived of their liberty**

**247.** The fact that there are no routines for highlighting disabilities of prison inmates also leads to a lack of respect for the individual's disability. Here we refer to the disability movement's alternative report on civil and political rights, article 10. No investigation has yet been carried out concerning physical accessibility in the Prison Service.

#### **248. COMMENT**

- In connection with detention, an individual plan must be drawn up of what treatment the individual is to receive. Within the framework of producing such a plan the causal connections that led to the detention must be examined to enable adequate care and treatment to be given. The plan must also be implemented.
- A survey of accessibility for persons with disabilities to premises within the Prison Service must be implemented. Such a survey must include physical environments, activities, information and also methods of communication such as deaf people's opportunities to communicate with guards and other inmates.

### **Children and young people**

**249.** As can be seen in the alternative report on civil and political rights, it is common for young people within the Prison Service to have neuropsychiatric disabilities. The Prison Services' report *Young Men in Institutions and Prisons (2001)* describes how young people with mental and neuropsychiatric disabilities do very badly in a prison environment. The fact that introverts are mixed with extroverts and that personnel within the Prison Service do not often have knowledge about which needs and conditions people with different neuropsychiatric disabilities have, makes the situation more difficult. More recent studies are not available.

**250.** The daily broadsheet newspaper Svenska Dagbladet (SvD) describes how children are locked up among sick adults<sup>50</sup>. The article tells of how many of the country's child psychiatric inpatient care wards break the rules of the UN Convention of the Rights of a Child, sometimes several times a month. Article 37 of the convention states that "Every child or young person who is locked up must be separated from adults". But the rule is not complied with. Instead, in many places children and young people are put together with mentally ill adults, by the occasional acute accident and by design. The most common reason for this is that children are considered too difficult to handle within psychiatric care facilities for children and young people. But there are also several examples of how underage patients have been moved to psychiatric intensive care, PIVA, or regular inpatient care wards for adults – solely because of lack of room or personnel. This has occurred in Karlskrona, Växjö and Stockholm. SvD tells of how unsuitable the atmosphere and environment is for children. Brutality is an everyday occurrence unlike what is normal for the Psychiatric Mental Health Care for Children and Adolescents (BUP). Many children tell of wards with nearly as many mechanical restraints as patients; of secured facilities and multiple locks on the doors. The personnel are not trained to meet children's needs and there is a risk that young people who are cared for at this kind of clinic develop new sorts of problems. At BUP clinics around the country both doctors and patients work to create security in close collaboration with parents.

#### **251. COMMENT**

- All those who come into professional contact with young offenders must receive training in the neuropsychiatric disabilities. Development of interdisciplinary knowledge must be encouraged.
- The government must institute vigorous measures so that young people in prison receive the care and support they need to enable re-integration in society.

#### **Deprivation of freedom and disrespect**

**252.** The disability movement would also like to stress that the actual deprivation of freedom must be carried out professionally and in a humane manner. Today, persons who are mentally ill are picked up by police who do not have any healthcare training or knowledge of how to treat persons who are mentally ill. The individual is treated more like a criminal than a person who is ill which is very disrespectful.

#### **253. COMMENT**

- People who suffer from acute mental ill-health must be treated in the same way as others who suffer from acute somatic conditions. There must be no doubt that a person who is acutely “mentally ill” shall be picked up by ambulance with a professional team of carers, not by police enforcements as is the case today.

**254.** The Disability Movement’s recommendations, see annex 2

## **Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment**

### **Article 15 1 Cruel, inhuman and degrading treatment**

#### **Lethal violence and compulsory care**

**255.** Depriving persons who have mental health problems of their freedom, as seen in article 14, is often executed in an unprofessional manner by police who do not have the necessary knowledge of how to treat a person who has mental health problems. The use of lethal violence is a very great risk in these cases. As seen in article 10, even the media have reported cruel deaths within psychiatric care. A group especially at risk are inmates who are emotional or suffering from acute confusion.

#### **256. COMMENT**

- Those charged with apprehending persons who suffer from mental ill health must be professionals who have adequate knowledge of how to treat a person who is suffering from acute confusion.
- Advice and guidelines concerning respectful treatment of inmates, who are emotional or confused, must be compiled.
- The National Board of Health and Welfare’s supervision must improve. Supervision must be carried out not only of the formalities of an activity but also of attitudes, treatment and content as well as the way the supervisory authority’s activities are designed. Users must be able to influence the supervisory authority’s activities. A survey into how this could best be achieved must be commissioned with an aim to take comprehensive control over matters of supervision instead of, as is currently the case, patching together and moving around bits of the existing system. The main question – for whom and for what the supervision is carried out – must be clarified.

### **Violence and threats within social services activities**

**257.** The County Administrative Board's questionnaire<sup>51</sup> of the occurrence of violence and threats in activities complying with LSS and SOL in the county of Västernorrland, found that of the 145 activities that responded to the questionnaire, 60 have experienced threats and violence between users and personnel. Of these, 17 said that it happens often and the rest said that it happens now and again. (33 percent say that violence and threats occur between users). A corresponding survey<sup>52</sup> was carried out in the county of Uppsala. It showed that of 151 activities that had received the questionnaire, 85 said that situations of threats and violence occur between personnel and users. Heads of units and managers working at 29 of these, say violent situations occur often. (Violence between users is said to occur in 51 activities).

#### **258. COMMENT**

- All forms of violence and threats are unacceptable and must be stopped. Personnel within all types of care services must be encouraged to report cases of violence and threats against residents or inmates with disabilities. Personnel must be provided with adequate in-service training and guidance about how to treat people with diverse disabilities.

### **Medical intervention**

**259.** Since 2007, county councils are obliged to report medical measures taken, for example electroconvulsive therapy, ECT, to the National Board of Health and Welfare's patient register. But according to the Board, this does not occur regularly. The register has only 1500 reported cases of ECT treatment for 2008. A survey carried out by a TV channel however found that ECT treatment has increased – from 18 000 cases per year at the beginning of the 21<sup>st</sup> century to 45 000 a year. In an attempt to form a picture of the use of ECT, the National Board of Health and Welfare has examined data concerning ECT and has had dialogues with patients, care personnel, experts and user organisations. The Board noted that care services must be better at following up and informing patients of the risks.<sup>53</sup>

#### **260. COMMENT**

- The outcome of the system's inadequacies, as described, is that it is impossible to see whether ECT is administered voluntarily or under compulsion. It is difficult, even, to see the extent of treatment, either with ECT or drugs, that is carried out according to evidence-based methods. Ways of ensuring that administering personnel, among who are psychiatrists, report cases of ECT and other medical interventions must be found forthwith. A system to handle these reports must be developed with an aim to clarify the quality and occurrence of such treatments and whether the treatment is voluntary or under compulsion.
- Informed consent is necessary for certain treatments. An inquiry is needed into whether an individual has received adequate information about the treatment and its consequences to be able to give such consent.

### **Article 15 2 Prevention measures**

**261.** The rules of the constitution protect all citizens against "violations of freedom". This protection can be restricted by law but there are no such restrictions in connection with activities complying with LSS and SOL. Violations of freedom, compulsion and violence are not allowed. Such actions are punishable by the laws of the Penal Code (BrB). However there is one regulation in RrB that gives exemption from responsibility, the indefensibility rule in chapter 24, section 4. This rule applies in general for all actions that would otherwise be considered criminal, and states that a person who acts out of necessity when danger threatens life or health, goes free from punishment. The indefensibility rule is intended to be used only in an emergency. The act must be "defendable" with regard to the nature of danger, the injury caused to another and the

circumstances in general”. The indefensibility rule must not be grounds for routine interventions. Chapter 3, section 3 of SoL, stipulates that all activities within the social services must be of good quality. For the implementation of the duties of social welfare committees there must be personnel with suitable education and experience. The quality of the work must be systematically and routinely improved and assured.

Section 6 of LSS stipulates “activities pursuant to this Act shall be of good quality and be conducted in cooperation with other relevant official bodies and authorities. The activities concerned shall be based on respect for a private individual’s right to self-determination and privacy. As far as possible it, it shall be ensured that the private individual concerned shall be allowed to influence and jointly determine the measures to be provided. The quality of the activities shall be systematically and continuously improved and assured. For the activities pursuant to this Act there shall be the personnel needed to enable good support and good service to be given”.

Provisions for work carried out to assure quality are regulated in The National Board of Health and Welfare’s guidelines and general advice to those responsible for the quality of activities according to SoL, LVU, LVM and LSS, SOSFS 2006:11.

Section 14 of SoL stipulates that all persons who work in care services for elderly people or for persons with disabilities must be careful to ensure that patients receive good care and that they live under secure conditions. A person who observes, or comes to know of, serious misconduct in the care of an individual must immediately report to the social welfare committee. If the misconduct is not dealt with without delay, the committee must report the incident to the supervisory authority. Similar obligations are found in section 24 of LSS.

#### **262. COMMENT**

- The disability movement has no points of view on the regulatory framework but considers that the supervision of residential care, care services and compulsory care must be developed further to cover personnel’s attitudes and the use of violence and other compulsory measures.

**263.** The Disability Movement’s recommendations, see annex 2

## **Article 16 Freedom from Exploitation, Violence and Abuse**

### **Article 16 1 Protection against exploitation, violence or abuse**

#### **Regulatory framework**

**264.** The Social Services Act (Socialtjänstlagen) prescribes that municipalities are responsible for making sure that women and children who are exposed to violence in close relationships receive support and assistance.

**265.** The Health and Medical Service Act (HSL) confirms that county councils are obliged to offer the entire population good healthcare on equal terms.

**266.** The social services, health and medical care and other authorities that come in contact with children and young persons are, under The Social Services Act, obliged to report immediately to the social welfare committee if, in the course of duty, they learn of circumstances where intervention by the social welfare committee is necessary to protect a child.

**267.** The National Board of Health and Welfare’s general advice (SOSFS 2009:22) concerning women who are exposed to violence and children who have witnessed violence, stresses the importance of taking responsibility for women with disabilities.<sup>54</sup>

**268.** The government has compiled a plan of action to combat men's violence against women, honour-related violence and oppression, and violence in same sex relationships. (Skr 2007/08:39). The plan has 56 items and aims to improve work carried out by the relevant authorities and organisations

#### **Monitoring current work**

**269.** The National Council for Crime Prevention (Brå), monitoring<sup>55</sup> the government's plan of action, found that several activities are ongoing. For example, many of those who work for the municipalities, within health and medical care, for the judiciary and voluntary workers, have taken part in study courses about violence against women, children who have witnessed violence and violence in same sex relations. Whether these courses throw light on the situation for girls, boys, women and men with disabilities is not recorded. The National Council's researchers note that in order to combat violence<sup>56</sup>, knowledge is needed about its reasons and extent, and the kind of efforts that could be successful in combating violence. As seen below, there is still no research concerning exploitation, abuse or violence against persons with disabilities.

**270.** A national survey<sup>57</sup> from 2009, notes, for example that all nine of the municipalities that were investigated in the Stockholm region, were found lacking. There are no activities for women with disabilities and older women, and a lack of knowledge. There were cases where neither politicians nor staff had reflected upon the need to make an effort for women with disabilities who are exposed to violence.

**271.** The survey<sup>58</sup> by The Swedish Association of Local Authorities and Regions (SKL) in 2009 to monitor the work carried out for women's peace in the municipalities, county councils and regions, found that plans of action and written guidelines for the work for women had increased during the past years, but only a few municipalities have ongoing activities for women with disabilities who are exposed to violence.

#### **Statistics concerning violence and abuse**

**272.** The National Council for Crime Prevention has investigated the extent of knowledge in existence about violence against persons with disabilities, has identified the competence that is needed and the possible ways of preventing violence. The inventory<sup>59</sup> shows that neither disability research nor criminal research distinguish sufficiently among diverse groups concerning sex, age, type and degree of disability. Research is largely based on small, non-representative samples of persons. One cannot, therefore, deduce whether violence against persons with disabilities has increased, decreased or changed over time.

**273.** The National Council for Crime Prevention's study notes that research does not show whether children with disabilities, in general, are more exposed to sexual violence than other children. Research does show, however, that children with disabilities are more exposed to bullying and breakdowns of care than others. The reasons given are, among others, that the children do not look the same, or behave in the same way as other children, and that parents of children with disabilities may bond less with them. At the same time, it is difficult to conclude whether the disability occurred before, or as a result of breakdowns of care or abuse. Research shows, too, that girls are more exposed than boys to different types of violence. Bullying, violence and different kinds of exploitation are most common among children with intellectual disabilities and physical disabilities. The violence occurs mostly at school in the form of bullying. Sexual abuse and breakdown of care occur mostly at home.

**274.** Research into men's exposure is limited. It has been found that men with extensive reductions of mobility or mental health disabilities are mostly abused indoors, in the home, in

special housing or in institutions. Persons known to them mainly carry out the abuse. It is assumed that the manner in which men with disabilities are abused differs from that of other men.<sup>60</sup>

**275.** A comparison of two national studies<sup>61</sup> covering violence against women with disabilities and women in general in Sweden, found that the numbers correspond. However, women with disabilities are exposed, to a higher degree, to mental violence. These women also felt more shame and are, to a higher degree, suicidal.

**276.** A survey carried out by the Swedish Research Institute for Disability Policy, Handu, “Men’s Violence Against Women with Disabilities”<sup>62</sup>, including answers from 1063 women with visual or mobility disabilities, notes that:

- A third, 33 percent, of those who responded to the questionnaire, said that they had experienced threats, violence or sexual harassment from men
- Half of these, a total of 14 percent of all those who answered, have once or several times sustained physical injuries inflicted by men who have exposed them to violence and sexual abuse.
- One in ten of all those who answered reported that their father had exposed them to violence before the age of 15. Other family members, mother, sister, brother had hit them.

20 percent of the women who answered said that they are now living, or have previously lived, together with a man who has exposed them to violence, threats or sexual abuse. Few have asked for, or received, support from society’s diverse institutions (see item 284-286)

Almost two out of three women with disabilities have once or several times in their lives been exposed to sexual harassment by men with whom they do not have a sexual relation. Seven percent have been harassed by drivers of special transport vehicles; this applies especially to age groups 18 to 34 years. Men, in connection with work or studies, have harassed one in four women. This happens especially to women with visual disabilities. 5 percent of the women have been troubled by care or service persons and two percent by teachers, psychologists or priests.

**277.** The research inventory carried out by the National Council for Crime Prevention found that women with intellectual disabilities were those at most risk of being exposed to violence, especially sexual abuse. Handu’s study<sup>63</sup> of women with moderate to slight intellectual disabilities found that:

- One in five has been forced to have sex and a third of the women have been hit before the age of 15.
- Six out of ten women have been exposed to sexual harassment and a third have been exposed to violence after the age of 15.
- One in ten has been raped by a man she has not had a sexual relationship with.
- One in ten has been raped by a boyfriend. And one in four of the women has had a boyfriend who has abused her in some other way. Eight out of ten were physically injured by the encounter. The police were notified in a third of the cases.
- Of women who have separated from a relationship where there were children, half say that the children were also harmed.

**278.** Women with mental disabilities are also an especially vulnerable group. The National Board of Health and Welfare’s review<sup>64</sup> from 2005, found that 63 percent of the women had been exposed to abuse after the age of 16. The corresponding number for last year was 31 percent. Another survey<sup>65</sup> referred to, concerning women who visited mental healthcare centres in Skåne, found that 70 percent had at some time during their lives been exposed to mental, physical and/or sexual abuse and/or financial exploitation. For further information see the alternative report, article 10 page 46 concerning economic, social and cultural rights.

**279.** Handu's standard of living survey<sup>66</sup> from 2005 notes that deaf persons are more exposed to violence than others in the survey, namely men and women with visual and mobility disabilities and those who are hard of hearing. The survey finds that deaf men are more exposed to gross violence, usually outside the home. Deaf women, along with hearing women, are exposed mainly to domestic violence.

**280. COMMENT**

- Funds must be set aside for research into the reasons for abuse and how it can be reported and remedied.
- Measures must be taken to ensure that municipalities include girls, boys, women and men with disabilities in their work, and combat violence, abuse and other forms of exploitation.

### **Article 16 2 Gender-and Age-sensitive Assistance and Support**

**281.** According to the government proposals<sup>67</sup> and to praxis in connection with the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), persons entitled to assistance may themselves choose their assistant. The same applies to those who receive support under the Social Services Act and who live in a municipality that practices "free choice". Persons, who live in municipalities where there is no "free choice" practice, do not have similar opportunities to influence the choice of assistant.

In connection with the government's plan of action to combat men's violence against women, honour-related violence and oppression, the National Board of Health and Welfare has been tasked to produce instructive compendiums concerning violence against persons with disabilities for the use of personal assistants and other health carers. The work should be done by September 2011. The national survey found that staff of special services caring for persons with disabilities also had little, or no knowledge about violence in close relationships.

**282. COMMENT**

- There is a lack of information about whether individuals can actually choose they own assistant. A survey to investigate this should be carried out.
- All people working with the care of persons with disabilities, in family and child care and with women's peace issues, must be offered information and training in how to recognise the occurrence of exploitation, violence or abuse against girls, boys, women and men with disabilities.

### **Article 16 3 Monitoring**

**283. COMMENT**

- Opportunities for independent authorities to carry out monitoring has improved lately. We welcome the wider mandate awarded the National Board of Health and Welfare, for instance, and we consider that things are proceeding in the right direction. The mandate and the manner in which the independent authorities carry out their supervision must continue to evolve.

### **Article 16 4 Protection and Recovery**

**284.** Handu's survey "Men's violence against women with disabilities" shows that two thirds of the women have never asked for, or received, support or help; despite the fact that many of the women have suffered both mental and physical violence. Of those who have had some support from society, almost as many are dissatisfied as satisfied with the help they received.

**285.** The survey carried out in nine municipalities and regions of Stockholm, finds inadequacies in many areas. One example is the lack of information adjusted to suit women with disabilities who have been exposed to violence and need support from social services. Many municipalities have no safe homes for women with disabilities. (See article 10, page 46 of the alternative report concerning economic, social and cultural rights.)

**286.** There are no permanent activities for deaf women and men who have been exposed to violence. Nor have the attempts made at various women's support centres to install text telephony evolved or been made permanent.

**287. COMMENT**

- There must be access to support centres for men and women in municipalities. This involves information about the support centres, communications with them and the physical environment at the centre. Municipalities must put pressure on voluntary organisations and give them financial support in order to render them accessible.
- There must be alternatives to the existing support centres that can cater for persons with special needs, among whom are persons with intellectual, brain damage, neuropsychiatric and mental disabilities.

**Article 16 5 The Regulatory Framework Covering Committed Crimes**

**288.** Criminal law's rules concerning crime and punishment apply to all people. The exploitation of a person's vulnerable situation, violence and abuse are, according to the Swedish Penal Code (Brottsbalken), crimes. If the defendant has exploited another person's vulnerable position, or ability to defend himself, special consideration will be given as to whether incriminating circumstances exist which will render a longer sentence. This is also the case if the defendant has exploited his or her position or special confidence. The Penal Code takes special note of whether a crime is committed against children or by a man against a woman in a close relationship.

**Legislation-free Zones**

**289.** Abuse is considered a criminal offence if there is a law that makes it possible to prosecute. Even though an act is criminal, the question is whether the perpetration is considered so. Studies<sup>68</sup> note that there is a tendency in health and special services care to look upon abuse that takes place between staff and resident, or between residents in care, as matters for healthcare, not legal matters. Incidents are not reported due to hierarchic structures that prevent junior personnel from daring to talk about the incidents, or report them. For her academic thesis, Astrid Kubis has studied abuse in special housing.<sup>69</sup> She finds that there are "legislation-free zones" in the homes. This applies especially when the actual perpetrator is a person with a disability. It could be about physical and mental abuse between residents, blows, pushing, threats or all kinds of insults. The violations were explained away, often with "he didn't mean it, he doesn't know what he is doing, or, he is otherwise usually so good".

**290. COMMENT**

- The regulatory framework notes the special vulnerability that persons with disabilities may be subject to. However, as seen in article 13, there are shortcomings in the manner in which legislation handles criminal offenders with disabilities. The National Board of Health and Welfare's supervision of health and medical care, together with other special care services should also cover analysis of how abuse is reported and dealt with.

**291.** The Disability Movement's recommendations, see annex 2

## **Article 17 Protecting the integrity of the person**

### **The Swedish disability movement considers that:**

**292.** To receive access to the various forms of support related to disability, persons are obliged to reveal all the intimate details of their private lives in a manner that must be considered incompatible with article 17. Individuals in need of various types of support are requested very offensively to say exactly where and when things take place. For example how long it takes them to have lunch, to take a shower or go to the toilet. An added danger as we see it, is the increasing use of indicators to assess a person's need of support. They replace a holistic approach and competent personnel.

**293.** There is not enough respect for a people's physical and personal integrity when they are deprived of their liberty due to mental ill health. Today, people with mental health problems are sometimes picked up by police who have no training in healthcare or knowledge of how to treat persons with mental health problems. People are treated more like criminals than patients. Even when a person is mentally ill and needs to be taken into psychiatric care, he or she must be treated with respect for their personal integrity, not in the offensive manner that is often the case today.

**294.** Psychiatric care in connection with compulsory care due to mental ill health must be carried out in collaboration with the individual. This is still not always the case in Sweden.

**295.** Individuals receiving care from municipalities' social services are often forced into many different contacts in order for their daily life to work. The various carers all have insight into a person's private life.

**296.** The Disability Movement's recommendations, see annex 2

## **Article 18 The Right to Liberty of Movement and Nationality**

### **Article 18 1 Nationality and access to identity documents**

#### **297. COMMENTS**

- The Swedish disability movement has no points of view on the regulatory framework concerning citizenship, documentation of nationality or other identity documentation or access to the immigration procedure.
- Access to support is decided by different officials. We refer therefore especially to the General Comment number 27 from the UN committee for human rights, that states that an individual's freedom of movement shall not be restricted by someone else's decision. Sweden still has considerable shortcomings in this area. For more information, see the conclusion and recommendations, article 12 of the alternative report on civil and political rights.
- The growing frequency of non-ionising radiation and the increasing trend for cordless electronic and technical products makes it difficult for persons with electromagnetic hypersensitivity to claim their right to move freely. The disability movement mostly welcomes technological growth but would like to underline the significance of all people's various health conditions being considered.

### **Article 18 1 B Immigration proceedings**

**298.** Persons with disabilities are covered by the same migration procedure as others. However, not enough attention is paid to chronic diseases and disabilities. The Swedish National Association of the Deaf notes, for example, that deaf asylum seekers very seldom have access to an interpreter in connection with the migration procedure, nor are there interpreters at refugee camps. There is no research into deaf asylum seekers' access to interpreters.

**299.** According to the Aliens Act, disability or severe illness are not reasons for granting permission to stay in the country. There is a possibility to apply for permission to stay due to “exceptionally distressing circumstances” but praxis is very restrictive. As shown in article 10 this has led to persons losing their lives. Article 7 describes how children with disabilities are sent back to their homelands where there is no access to necessary medical care, assistive devices or training in sign language.

**300.** As seen in the alternative report concerning the convention on the rights of women, it is often difficult for women with immigrant backgrounds to profit from the right to independently apply for new citizenship, to live where they wish, to chose a partner etc. There is no information about opportunities for women with immigrant backgrounds and disabilities.

#### **301. COMMENT**

- The Migration Board must be commissioned to account for how their various units work to observe and consider disabilities that may appear in any part of the immigration proceedings and also in refugee camps.
- Information concerning women with immigrant backgrounds and disabilities’ real possibility to profit from freedom of movement as stipulated in this article must be provided.

### **Article 18 1 c Freedom to leave the country**

**302.** It is often not possible for persons who need interpreters, guides or personal assistants to travel abroad because the application asking for permission to travel with guide, interpreter and assistant is rejected. See article 20.

### **Article 18 2 Children’s right to a nationality**

**303.** The Swedish disability movement has no points of view on children’s right to a nationality, name and registration at birth. Children’s right to be cared for by their parents when possible is discussed in article 23.

**304.** The Disability Movement’s recommendations, see annex 2

## **Article 19 Living independently and being included in the community**

### **Article 19 A. Place of Residence**

#### **Regulatory framework**

**305.** People with disabilities have equal rights with others to choose their place of residence and where and with whom they live. Dissimilarities in communities' praxis, however, sometimes limit the individual's possibility of moving house or living area. (See further Article 19 B and 20.)

**306.** Those people who are included in the “Act concerning Support and Service for Persons with Certain Functional Impairments”, LSS, are entitled to sheltered housing, including so-called group living and service homes. The individual, he or she, must always make the application in these cases.

**307.** The Act on Housing Adaptation Grants (SFS 1992:1574) states that individuals with a disability, and who are permanent residents, are entitled to a housing adaptation grant in order to adapt their home to their special needs. However, there are restrictions in the law concerning the

possibility of changing places of residence. §9 states that there must be special reasons for the purchase or change of housing in order to receive adaptation grants.

**308.** Accessible housing areas are important so that people with disabilities are able to live inclusively. Building regulations concerning accessibility also apply to planned buildings, buildings under way or undergoing reconstruction. However, the regulatory framework needs supplementing. (See further Article 9 items 115-126). Also for existing housing areas, the regulations are insufficient. For example there are no provisions for accessibility to communal facilities.

**309. COMMENT**

- The overall regulatory framework concerning building, including the provisions relating to construction laws, must be revised and supplemented so that more homes and housing areas are made accessible for people with disabilities. “The Act on Housing Adaptation Grants” must be revised so that people with disabilities enjoy equal opportunities with others to choose whether to stay put or move from their home.

**Statistic comparisons**

**310.** The Swedish Board of Housing, Building and Planning (Boverket) monitors the development of housing with special services for people with disabilities and who are covered by LSS. The situation has deteriorated somewhat over the last few years. Two out of three municipalities are in need of more sheltered housing. About 20 percent of municipalities have a shortage even after planned buildings are in place.

The same survey<sup>70</sup> shows the number of municipalities that work with issues of accessibility, for homes and housing areas and for public environments. However, the survey does not show the level of accessibility, but, it states that in 2008, 54% of the municipalities reported that accessibility in housing areas was on the agenda as a highlighted item, compared to 35% in 2003. The Swedish Disability Federation's project “Accessible Housing Areas” investigates possibilities and develops methods to facilitate work for accessibility in existing residential environments. The project recognises that builders and contractors are quite willing to create housing with good accessibility, but often lack the knowledge to achieve it.

**311. COMMENT**

- Information about the regulatory framework, guidelines and examples of how to create accessible housing areas must be conveyed to all who are involved.

## **Article 19 B. Access to community support services**

### **Regulatory framework**

**312.** The two main laws that regulate the amount of support people are entitled to so that they can live independently and be included in society are:

The Social Security Act (Socialtjänstlagen, SOL) includes all people in society, with or without disabilities. Benefits, as stipulated in SOL, are given to sustain reasonable living conditions. Benefits are “sustenance support and benefits for life in general”. Municipalities use means-testing to establish a person's needs, such as cleaning, laundering, shopping, cooking or other personal services.

The Act Concerning Support and Service for Persons with Certain Functional Impairments, LSS, is aimed at people with extensive disabilities that cause significant difficulties in daily life, thus creating the need for extensive support and service. The Act offers ten different activities, among them support and advice, personal assistance, escort service and a contact person. If a person covered by LSS needs personal assistance for more than 20 hours a week the, cost will be

met by The Swedish Social Insurance Agency (Försäkringskassan) instead of the municipality. The allowance is called assistance allowance in keeping with the Act covering this field, LASS.

### **313. COMMENT**

- The laws' intentions are good, but they need to be clarified so that individuals, regardless of where they live, are guaranteed assistance in accordance with the provisions of the CRPD.
- The wording of The Social Security Act allows many interpretations, thus causing very few municipalities to grant escort service when needed and free of charge, or help in the home where the user decides what needs to be done.
- The wording of LSS is unclear when describing who qualifies for group three. Many municipalities turn down applications from persons with extensive "permanent physical or mental disabilities that cause severe difficulties in daily life" even though these are accordance with the law. For example escort service for people with severe visual impairments who really need the help.

### **Statistical comparisons and research results**

**314.** In a questionnaire<sup>71</sup> for people who are both deaf and blind, a third of those who need an escort said they cannot take a walk outside as often as they would wish.

**315.** Although Finnish is one of Sweden's minority languages, a survey undertaken at local level of The Swedish-Finnish Association of Visually Impaired, shows that it is difficult to get disability support in Finnish. There is, for example, in only 9 of 16 municipalities a Finnish-speaking home carer. In only 9 of 15 municipalities is it possible to find a Finnish-speaking escort. 9 of 15 districts or municipalities lack interpreters in Finnish for people with visual impairments who visit the theatre, or a film or some other cultural event.

### **Changes in the interpretation of the law**

**316.** The right to personal assistance is based on a person's fundamental needs as stated in LSS. In Autumn 2007, The Social Insurance Agency published, in an internal information sheet (IM 2007:161), a new legal interpretation of how fundamental needs for personal assistance should be judged. The judgement of how much help is needed for dressing and undressing, hygiene and at mealtimes was narrowed down. The result is that many people have had their benefits reduced or cancelled. The Swedish Radio reported that 143 people lost their assistance benefits during the first six months of 2010, showing that the process is accelerating. In 2007, 57 people lost their benefits, 100 people in 2008, 146 in 2009 and now 143 people during the first six months of 2010.

### **Legal Praxis**

**317.** In June 2009, The Supreme Administrative Court, (Regeringsrätten) established a precedent, case number 5321-07, laying down a new restricted interpretation of the conception "fundamental needs". The Court considers that "fundamental needs concern meals, personal hygiene, dressing and undressing and visits to the toilet." "Concerning the time AA has estimated for help in connection with meals, according to his own report, he manages, among other things, eating and drinking on his own. He can also pour a drink into a glass and serve himself when food is put on the table. What he needs help with is preparing and cooking food, and clearing up afterwards. He also needs help cutting tough meat or when a knife and fork are necessary."

The Supreme Administrative Court finds that these needs are not of the personal and integrity-sensitive kind that should be taken into account when judging his right to personal assistance. The time AA has estimated for meals shall therefore not in any way be taken into account in so far as the question of his need of support meets the fundamental needs"

### **318. COMMENT**

- The Social Insurance Office and The Supreme Administrative Court 's new interpretations of fundamental needs as written in LSS, vary considerably from the intention of the law and must also be considered inconsistent with Article 19.

### **Sign language and other interpretation**

**319.** For deaf-blind people, for the deaf and for many people hard of hearing, access to interpreters is a prerequisite for participation and inclusion in society. The Health and Medical Service Act (HSL) states that county councils are obliged to provide those living in the county with interpreting in connection with healthcare (3b§). The interpretation service is an obligation for county councils, not a special right for the individual.

Complaints concerning absent or substandard interpretation can be made to the council's patient association. The association cannot, however, appeal or change a decision concerning interpretation.

**320.** In a questionnaire<sup>72</sup> targeting deaf-blind people, over half of those who use interpreters, said that they do not always have access when they need one. In 2009/2020, 162 complaints concerning absent sign-language interpreters have been sent to The Discrimination Ombudsman (DO). The DO has, however, not pursued any of the cases because this is not considered to be discrimination in the eye of the law.

**321.** A government decision in 2008, commissioned The National Board of Health and Welfare (Socialstyrelsen) to monitor how the regulations for everyday interpretation are applied and to clarify what the concept implies. The National Board of Health and Welfare presented its conclusions in the report The Concept of Everyday Interpretation (Begreppet vardagstolkning). The survey shows that many of the bookings for everyday interpretation are successful, but the councils' results are very varied. The Board notes that there are problems among which are interpretation for activities undertaken outside working hours and for social events. There are examples of instances when the user chooses not to book an interpreter for certain situations, because he or she knows how difficult it is to get one. This occurs with all types of interpretation, written and tactile for example. Statistics and stocktaking of needs are inadequate.

#### **322. COMMENT**

- A national coordinator of interpreters is needed for all types of interpretation required by deaf-blind people, people with childhood deafness, deaf adults or people hard of hearing. Only county councils should be responsible for booking and delivering to the users. Funds should be available on a national basis.

### **Article 19 C. Access to community service**

**323.** There are laws in Sweden that aim to make the physical environment accessible for people with disabilities. As seen in Articles 9 and 25, these laws are not always complied with. Care for the elderly, and housing, often lack access to technical aids for people hard of hearing, such as alerting devices, communicators, telephone aids/text phones, loops in public locations and connected to televisions, a satisfactory environment of sound and accessible alarm systems, for example a fire alarm. Furthermore, the home carers and carers of the elderly often lack the competence to give correct advice.

#### **324. COMMENT**

- Negligence of established legal measures concerning accessibility should be deemed as discrimination.
- The regulations concerning accessibility must be supplemented in accordance with the recommendations under Article 9 so that information and communication related to community service is made accessible for people with disabilities on equal terms with others.
- Information campaigns about disabilities and disabling factors must be organised for all who work in the public sector.

**325.** The Disability Movement's recommendations, see annex 2

## **Article 20 Personal mobility**

### **Article 20 A. Facilitating personal mobility**

#### **The Regulatory framework**

**326.** Of great significance in enabling persons with disabilities to move around as they wish and when they choose, is that transportation, buildings and information in connection with travel are accessible. There are still huge shortcomings of accessibility in Sweden. For a description of the regulatory framework and statistics on accessibility see article 9.

**327.** The Special Transport Act regulates municipalities' decisions of special transportation for its inhabitants.

**328.** According to the Special Transport Act's provisions concerning special transportation around the country, a municipality grants an allowance for the travelling costs of a person who due to disability is obliged to travel more expensively. The allowance should also include a guide or an assistant if needed during the journey. According to the law, permission is issued together with method of travel. Undertaking such a journey, the traveller pays a fee equivalent to "normal" ticket prices on public transportation. The government decides the fee.

**329.** The law on Car Allowance prescribes that people who, due to permanent disability, cannot move on their own or use public transport, are entitled to car allowance. This government grant can also be given to parents with children who have disabilities. The allowance covers the procurement and adjustment of a vehicle. Under certain circumstances, funds are provided for acquiring a driver's license. Car allowance is mainly granted to persons who are "connected" to employment (actually have a job, take part in labour market training courses, partly on sick leave, vocational re training or similar activities). Others cannot receive car allowance until they reach 50 years of age.

#### **330. COMMENT**

- The regulatory framework covering transportation must be supplemented in accordance with the disability movement's comments under item 139 in article 9, to enable personal mobility in a manner prescribed by the convention.
- As is seen below, municipalities interpret the laws on special transportation very differently. Hence, the law must be clarified to strengthen the right and practical use of an individual's possibility to move freely within, between and over the boundaries of a municipality.
- National guidelines concerning how special transportation is organised, how permission is granted and the rate of fees charged must be introduced, so that equal quality special transportation is available to persons with disabilities wherever they live.
- A car can replace legs, a bicycle, a bus and other means of transport connected to personal mobility, and can make it possible to participate on more equal terms. However, the individual's chances of receiving a car allowance have dwindled. The regulatory framework must be reviewed.
- The strong link that the car allowance has to employment and the age limit must be eliminated. Need, not work or age, must be the decisive factor for granting car allowance.
- The allowance must be raised. The current sum is from 1992 even though the inquiry that presented reforms of the allowance clearly said that the allowance should follow the cost trends of cars.
- Opportunities to receive car allowances must be extended to persons who are electrohypersensitive.

## Statistical comparisons and research results

### *Accessibility to public transport and roads*

**331.** We refer here to a questionnaire<sup>73</sup> concerning how persons who have suffered strokes assess accessibility to public transport. It found that very few had travelled by any means of public transport over the past years. 9 percent had travelled by train. 80-82 percent of those who had not, but would like to travel by train said that the obstacles were of a physical nature, that is to say getting to and from the trains, getting onboard and getting off. 37 percent had cognitive difficulties that prevent travelling. See item 137.

**332.** Pedestrian crossings are increasingly “silent and unmanned” and this limits the mobility of persons with visual disabilities. An inquiry carried out by The Transport Administration is currently looking into how roads are designed “Vägars och gators utformning”(VGU). Municipalities are not obliged to comply with VGU, it delivers only guidelines.

### **333. COMMENT**

- The Swedish Transport Agency’s VGU must be upgraded so that its recommendations lead to an acceptable level of security and increased opportunity for persons with disabilities to orientate in traffic.
- It must be compulsory for municipalities to comply with the guidelines of VGU.

### *Travelling with special transport services*

**334.** The report<sup>74</sup> Special Transport Service and Inter-Municipal Transport Service notes that on 31<sup>st</sup> December 2009, 328 164 persons had special transport licenses.

In 2009, more women than men were entitled to use special transport services (46 per 1000 women; 24 per 1000 men). The discrepancies can be explained by the fact that it is usually elderly people who use special transport and women, on average, live longer than men. Only the age group 0-19 years has a marginally higher percentage of male license holders.<sup>75</sup>

73 percent of persons who have suffered strokes use special transport while 7 percent would like to but as yet do not have permission.

**335.** Swedish Radio in Jönköping reported in August 2010 that municipalities’ expenses for special transport services are very varied. The differences are presumed to be caused by municipalities’ varying decisions as to who is entitled to use special transport services<sup>76</sup>. The radio programme Kaliber reported in 2006 on special transport services in Sweden’s municipalities. A questionnaire that was sent to the municipalities showed that the law is interpreted very differently and that the municipalities’ regulations for special transport were very varied.<sup>77</sup>

The fees for special transport of escorts and assistants diverge. Some municipalities charge extra for assistants and escorts.

There is no data concerning whether there are municipalities where persons with disabilities cannot access special transport services.

**336.** One survey<sup>78</sup> covering users’ views on special transport describes how users have mixed feelings. On the one hand they are glad that special transport exists to make everyday life possible; on the other hand it is society that lays down the terms, not the users.

Special transport is not a choice but usually the only alternative. The disability movement’s alternative report on civil and political rights describes how the increasingly limited municipality regulations have led to restricted mobility for the individual. The interviewees who are politicians

with disabilities highlight their difficulties in getting to and from meetings. (More information at article 29, item 552).

Not being able to travel spontaneously due to special transport having to be booked several weeks in advance<sup>79</sup> is something many users point to. How long a journey will take cannot be planned in advance because of car sharing and this is also a problem.<sup>80</sup>

Transport services' companies do not consider this kind of spontaneous travel to be cost effective. The difficulties in connection with inter-municipal transport are also mentioned and considered to be out dated both by users and drivers. But because the limitations surrounding inter-municipality travel – without special permission – have legal support, the problem still exists.<sup>81</sup>

### **337. COMMENT**

- Special transport services are a necessary form of transport and must be seen as a replacement for users' legs, arms, bicycle, car, bus and train. They are also the only means of public transport on offer for persons with certain types of disabilities. Smoothly running special transport services ensure relative independency for people with disabilities and less dependency on others. Making cuts within special transport services could also mean higher costs for other sectors, for example home caring.
- The principles of fundamental freedom of movement and the right to move when, to where and as often as one chooses must be paramount to the desire to reduce costs.
- Special transport services must be more flexible. Travel across county and municipality borders must be easy.

### **National special transport services**

**338.** Municipalities also interpret the regulations concerning national transport services differently. The fee charged for national transport is decided by the state. However municipalities sometimes decide the type of transport to be used for example special vehicles, taxis, planes or trains; despite the fact that the high-speed trains X2000 for quite long periods of time, have not been accessible for wheelchair users. Municipalities' right to make decisions concerning method of travel also means that an individual cannot choose to travel more cheaply, for example the cheapest airline or reductions for train travel at certain times of the day.

The law covering national special transport services stipulates that licenses include escorts when needed during a journey. If the escort is not needed during the actual journey but at the destination, the individual runs the risk of having to pay the fee for the escort's journey as well.

### **339. COMMENT**

- National guidelines for special transport services must be issued so that the quality of national transport services is equal to that of the services provided for persons with disabilities regardless of where they live.

### **Gender divide in case law**

**340.** Decisions concerning special transport services, national special transport services and car allowances can be appealed. National comparisons<sup>82</sup> from 2001 found that it was more difficult for women to have a decision changed. There are no more recent national surveys, but regional studies have been carried out. In 2005, 1672 decisions concerning special transport services in the Stockholm region were appealed. Among those who have not had their needs met in decisions made by county administrative courts, 60 percent are women and 31 percent men.<sup>83</sup>

## **Article 20 B Assistive devices and assistance**

**341.** For overall information about assistive devices see article 26, items 467-470.

For overall information about assistance and intermediaries see article 19, item 312.

Persons who need interpreters, escorts and personal assistance are sometimes prohibited from travelling abroad because their applications for escorts, assistance and interpreters are denied. The possibility of travelling with interpreter, escort and assistant is greater, but still very restricted, if the journey is for work or study. For more information see the disability movement's alternative report on civil and political rights article 12 pages 73-74.

**342. COMMENT**

- Every time an individual is denied the right to travel with an interpreter, an escort or an assistant, the individual right to leave the country is disregarded.

**Article 20 C Training in mobility skills**

**343.** As can be seen in article 26, item 460, it is difficult to obtain an overall picture of the quality and extent of county councils' activities for habilitation and rehabilitation. Because county councils' accounting systems do not cover habilitation and rehabilitation, it is not possible to follow up either needs or resources in a satisfactory manner.

**344. COMMENT**

- To obtain knowledge about the extent and quality of training in mobility skills it is necessary for accounting systems to include rehabilitating and habilitating activities for men and women and boys and girls with disabilities.

**Article 20 D Aids and devices for mobility**

**345.** The disability movement has no points of view on this issue. Most county councils, who are responsible for the prescription of mobility aids, work closely together with representatives of the disability movement in the development of these aids.

**346.** The Disability Movement's recommendations, see annex 2

**Article 21 Freedom of Expression and Opinion, and Access to Information**

**Article 21 A. Information intended for the general public**

**The regulatory framework**

**347.** The Swedish principle of public access to official documents is laid down in the Freedom of Information Act (Tryckfrihetsförordningen) which is one of Sweden's constitutional laws. In chapter 2, §1, it states "To promote free expression and comprehensive information, every Swedish citizen shall have the right to share the content of public documents".

**348.** "The ordinance (2001:526) concerning government authorities' responsibilities for persons with disabilities", obliges government authorities to increase accessibility to, among other things, information. Municipalities do not have similar responsibilities. There is, however, no obligation for either national or local authorities to provide information in the medium chosen by an individual as the most usable, for example in Braille or digitally. See Article 9 for authorities' decisions. There is a lack of regulations for this area in society at large.

### 349. COMMENT

- Regulatory must be introduced. Municipalities must be charged with making their information to the general public accessible to persons with disabilities. Individuals must have the right to receive information in the medium they find usable.

## Statistical comparisons and research results

### *Access to public records*

**350.** On June 22<sup>nd</sup> 2009, The disability movement tested by random sample, whether the principle of public access also applied to people with disabilities. Its representatives visited a few central government agencies to discover if it was possible to access various documents in formats other than “ordinary text” on paper, for example in Braille or digitally. None of the authorities could provide information in optional formats. A few authorities said they would let the representatives know when and if they found the required information. The agencies approached were The Government Offices (Regeringskansliet), The Social Insurance Office (Försäkringskassan), The Post and Telecom Agency (Post-och telestyrelsen), The Ombudsman for legal matters (Justitieombudsman) and National Board of Trade (Kammarkollegiet).

### 351. COMMENT

All public players must have the routines and the equipment to ensure that all people, regardless of disability, have access to the information they require.

### *Access to public websites*

**352.** Sweden does not yet have a comprehensive follow-up system for public websites. Recently, the government agency Verva surveyed a thousand websites for certain codes. The last survey<sup>84</sup> from 2008, showed increased accessibility to public websites but the increase is very slow. Only 21 percent had a front page that used recommended guidelines. This is an increase from 6 percent in September 2005. 45 percent of government authorities' websites, as shown in Handisam's questionnaire from 2010 are accessible. 46 percent said that their websites are not accessible but that they are working on it, 6 percent said their sites are not accessible. A total of 271 authorities answered the question.

### 353. COMMENT

- All public players must follow existing guidelines for websites and other electronic communication
- Guidelines for accessible electronic communication must be drawn up for the areas that still do not have them. The disability movement must be involved in this process.
- The disability movement must receive public funds to enable it to partake with points of view in the work to produce the guidelines.

## Article 21 B. Use of accessible information, communication and facilities

**354.** The use of facilitating techniques in public environments is unusual. As shown above, government authorities are obliged, since 2001, to make their activities and information accessible to people with disabilities. In spite of this, Handisam's survey of authorities in 2010, found that only 40 percent of those who answered the question had facilities for people hard of hearing installed in their main locations (26 percent said yes in one building, 34 percent said no). Asked whether their main offices are equipped to function for people with visual impairments, 50 percent said glass doors are marked at eye-level, 47 percent said they had tactile marking in the lifts and 27 percent said they had a voice in the lifts to announce the floors. 40 percent said that all their stairways were contrast marked. Even today, it is far from routine procedure to cater for the use of, for example, writing and drawing aids and sign language in public buildings.

### **355. COMMENT**

- Regulatory framework must be introduced in order to promote the use of facilitating technology.
- Negligence of established regulations for accessibility must be judged by law as discrimination. At the present time, there is no effective legislation relating to Article 21

### **Article 21 C. Individual service suppliers**

**356.** The Public Procurement Act (Lagen om offentlig upphandling) states that when public players make technical specifications, they must take into account accessibility for people with disabilities. The law covers public procurement of buildings, commodities and services and public works' concessions and contracts.

The law does not, however, contain regulations concerning whether commodities or services should be accessible, nor does it stipulate that accessible information should be at hand. Neither does the law cover the procurement of services and systems for information and communication. As shown in Article 27 for example, The Social Insurance Office has purchased a computer system that cannot be used by "Braille readers", (which resulted in people with visual impairments being refused work there.)

### **357. COMMENT**

The Public Procurement Act must be supplemented with:

- provisions to insure that information about the services and goods purchased by public players is accessible.
- provisions to regulate the procurement of goods and services in connection with information and communication.

### **Article 21 D. Media**

**358.** From the first of August, 2010, there is a new "Radio and Television Act" in Sweden. The law gives the government an opportunity to increase participation for people with disabilities by regulating accessibility. "The Authority for Radio and Television" has reported that it plans to start preliminary work in the autumn of 2010.

### **359. COMMENT**

- The Swedish government and The Authority for Radio and Television must with all possible speed make full use of the law. There are already techniques for making the media more accessible, for example texting, visual interpretation, text reading and more, and they must be used. The disability movement expects to be approached as soon as possible so that its views on current regulations are considered in a constructive way.

### **Article 21 E. Sign language**

**360.** In Sweden, Swedish sign language is one of the national minority languages. According to The Language Act (Språklagen), the "public sector" has a particular responsibility to protect and promote the national minority languages and the Swedish sign language. "The public sector" consists of bodies that perform tasks for the public at all levels. The Language Act is a so-called obligatory law. This means that it charges the public sector with an obligation (to take active measures to safeguard languages so that they remain usable in Sweden). It is not a law of rights and does not give individuals the right to receive sign interpreted information. About access to information and communication in connection with authorities see Article 9.

### **361. COMMENT**

- Targeted resources for Swedish sign language interpreters are scarce in Sweden. This limits both the individual's access to interpreters and the public's opportunity to promote Swedish sign language as advocated in The Language Act. The law has not lived up to its expectations. If the content of the Language Act is to be realised, funds must be continuously earmarked for Swedish sign language interpretation. The use of Swedish sign language and access to interpreters must increase if Sweden is to live up to Articles 9,19,27,29 and 30.

### **Children of the deaf, the deaf-blind and people hard of hearing are advised against learning more than one language**

**362.** Although people with childhood hearing loss testify to the advantages of having more than one language, Swedish sign language and the spoken language, there are cases where parents are advised against giving their child access to Swedish sign language communication.

### **363. COMMENT**

- All children hard of hearing must be offered Swedish sign language courses. Anything else must be inconsistent with Article 21.

**364.** The Disability Movement's recommendations, see annex 2

## **Article 22 Respect for Privacy**

### **Article 22 1 Interference in privacy**

**365.** The Swedish disability movement wishes to emphasise here the occurrence of arbitrary and offensive deprivations of liberty that always interfere hugely with privacy. More information on the subject can be found in article 14 of this report.

#### **Interference in a child's privacy**

**366.** The ombudsman for children (BO) was authorised by the government in 2010 to report on children's and adolescents' opinions about family homes and care homes and supported living service (HVB). BO's annual report in 2010 notes that interviews with young people revealed that children's rights to privacy and family life are put aside when their opportunities to telephone friends and family are, with no legal support, routinely restricted. Some of them spoke of forced separations carried out on false grounds. BO notes that current legislation concerning children placed in care is repressive and focuses on restrictions and compulsory activities that dominate the children's lives. Legislation lacks a clear perspective of rights that evolves from a child's circumstances and what a child has the right to expect of care.

### **367. COMMENT**

- It is clear that the regulatory framework has not been sufficiently amended as a result of Sweden's ratification of the children's convention and the convention of rights for persons with disabilities. The legislation must be reviewed and amended so that harmful, arbitrary and unnecessary interference in children's privacy is prohibited.

#### **Interference in adults' privacy**

**368.** In the summer of 2006, parliament approved amendments to the law concerning compulsory psychiatric care (LRV) that made it possible for a head senior consultant to:

- o restrict a patient's right to use a mobile phone and other electronic communication devices
- o monitor a patient's letters

The amendments took effect in July 2006. The outcome is that decisions about restrictions or monitoring may be made if it is considered necessary for the care and rehabilitation of a patient, or to avoid harm coming to others.

The decision is temporary and valid for two months. The head senior consultant must regularly consider whether the restrictions and monitoring can be terminated. The patient can appeal the decision to the county administrative court. The technical equipment is confiscated for the duration of the restriction. A decision must not restrict a patient's right to freely contact, in writing, a lawyer or counsel, supervisory authority or other authority, or international body that Sweden has acknowledged as eligible to receive complaints from individuals.

#### **369. COMMENT**

- The aim to protect a patient, and avoid harm coming either to the patient or some other person, by confiscating electronic communication devices, is reason enough for the inclusion of new rules. However, the disability movement can only accept the law's regulations if careful supervision is in place and that senior consultants are obliged to cooperate with the patient and his or her family before a decision about restrictions is made.
- In order to minimise the risk of improper interference in people's privacy, the manner in which courts judge cases of interference in people's privacy, of deprivation of liberty, of compulsory medication as well as courts' independency in relation to doctors/psychiatrists, must be analysed. The gender aspect must be considered in such an analysis.

### **Article 22 2 Confidentiality**

**370.** The Public Access to Information and Secrecy Act (2009:400) regulates areas subject to secrecy. An individual's personal data are subject to secrecy if it is not absolutely clear that the data can be disclosed without causing grief to an individual or a person close to the individual. Confidentiality is more vigorous within municipality family counselling than in the social services. It is prohibited to reveal data about an individual unless he or she has given permission.

#### **371. COMMENT**

- There is no information about how the regulations are complied with or to what extent confidential information is transferred, for example, when one care coordinator takes over from another.

**372.** The Disability Movement's recommendations, see annex 2

### **Article 23 Respect for Home and the Family**

#### **Article 23 1 A The right to marry and found a family**

**373.** The right to marry and found a family encompasses all people in Sweden. There is no comprehensive material concerning the extent to which persons with disabilities marry and found families compared to others. Defined surveys carried out by the National Board of Health and Welfare show, however, that:

- Families of persons with intellectual disabilities or severe mental or physical disabilities differ from those of the rest of the population in that, among other things, fewer marry and have children.<sup>85</sup>
- Divorce is more common in families where someone has a disability.<sup>86</sup> (for more information, reasons and consequences, see the alternative report on civil and political rights, article 23)
- Serious illness can put great pressure on relationships with partners, children and other members of family.<sup>87</sup>

- A follow-up<sup>88</sup> of the situation two years after a stroke found that more than half of those who had suffered strokes relied wholly or partly on help from the family. Research<sup>89</sup> on spouses of stroke patients found that they suffer great pressure. The National Board of Health and Welfare notes that a consequence of this is the increased risk of separation or finding it harder to form new relationships.

**374.** Since July 1<sup>st</sup> 2009 the country's municipalities are under obligation to provide support for family members who care for or support someone who is chronically ill, elderly or has a disability.

**375. COMMENT**

- The impact on a person in the prime of life who contracts a chronic disease or a disability is huge and the family will also suffer. When a family member contracts a chronic disease or a disability, it is crucial that not only the "sufferer" is given support, but that the family is also supported so that everyday life works.
- Regardless of whether a disability is contracted before or after starting a family, the individual's "role" in the family and his or her responsibility must be taken into account when support related to the home and family is given. Decisions must not be based on a civil servant's views on gender or disability.
- Families of persons with disabilities and chronic diseases are a heterogeneous group. The need for support can differ. "Elderly" and younger family members may have different prerequisites for helping a family member with a disability. Family support must be available in the evenings for family members who work during the day.

**Article 23 1 B Family planning and sexuality education**

**376.** According to the Social Security Act, municipalities are responsible for providing family counselling if required.

Schools' steering documents state that schools must give all children and young people sexuality education. The national federation for sexual information, RFSU, and the Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights, RFSL, regularly organise study courses and advice on sex and family issues. It is not clear whether persons with diverse disabilities have access to adequate advice about sex, families and family planning. There is no comprehensive survey on how information about sex and family issues covers the aspect of disabilities.

**377.** The National Board of Health and Welfare made an inventory of Swedish and international research concerning parents with disabilities and their children. It found that research lacks a gender perspective. Only 1 of 18 Swedish studies on parents with disabilities mentioned a father.

**378. COMMENT**

- A survey must be carried out to look at supply, information, quality of study material and training courses and counselling. Such a survey should also consider study courses for fathers with diverse disabilities.

**Pregnancy and anti-natal care**

**379.** Maternity care is free and available to all women. The clinics can, beside pregnancy checkups, also provide help with the choice and prescription of different contraceptives, counselling and testing for venereal diseases, smear tests and preventive care. There is specialist anti-natal care for pregnant women who for example take medicine or need to adjust the dose, or women who need a gynaecologist with special skills in anti-natal care and giving birth.

### 380. COMMENT

- In general, Sweden's anti-natal care works well. However, there are no available studies about accessibility to clinics' premises or chairs for gynaecological examinations, or the possibility of accessing information about pregnancy, giving birth and parenthood.

## Article 23 2 Care, adoption and support

### Care

**381.** The fundamental regulations covering care of children are found in The Parents and Children Code, chapter 6, section 3. It states that both parents have guardianship of a child from birth if the parents are married to each other, otherwise the mother alone. If parents marry each other later on, they have joint guardianship of the child from that point in time. Unmarried parents can have joint guardianship of their children through a court decision, by notifying social services in connection with paternity tests or – unless an earlier court decision has been made about custody – by notifying tax authorities.

The provisions of the Parents and Childrens Code cover all people regardless of disability.

### 382. COMMENT

- Because persons with intellectual disabilities do not marry<sup>90</sup> as often as the rest of the population, the possibility of a father receiving guardianship is not clear, hence also the relationship with the child. If the mother loses guardianship of a child, the father also loses his right unless he has previously been active in demanding joint guardianship.
- Social services must ensure that all fathers receive understandable and relevant information about guardianship of children.

### Adoption

**383.** Before adopting a child, consent must be given from social services in the home municipality;

and before a decision is made, an officer from the social services investigates the case. If the investigation reveals illness or disability, the case is sent to the National Board of Health and Welfare's Legal Advisory Council. The Council carries out a special investigation assisted by doctors and other medical experts and sends a proposal for the decision to the officer who makes the final decision about the suitability of parenthood<sup>91</sup>.

The social services' handbook on issues of adoption states that a person who needs personal assistance may find it difficult to bond with the child<sup>92</sup>, and this should be taken into account.

**384.** The rules for international adoptions were amended in 2005. The National Board of Health and Welfare's report about international adoption and new demands on presumptive parents looks at municipalities' work with adoption issues since the law was amended. The report found that decisions are now made more for the best of the child. This means that the presumptive adoptive parents are investigated for mental, physical and social abilities. In a description of how the new rules should be applied, the National Board of Health and Welfare says that it must be clear that illness or disability do not affect the ability to be a good parent.<sup>93</sup> Because of adopted children's background and circumstances it is not advisable to place them in families where illness or disability make it difficult for the adopted parents to meet the needs of the child, such as a sense of belonging, stability, continuity, closeness, care, security and stimulation. The risk of not being able to cope, long periods of sick leave or hospitalisation or medication with side effects that lower a person's capacity etc, pose a risk that a presumptive parent may have difficulties in serving the best needs of the child.<sup>94</sup>

In a study on modern rules of adoption<sup>95</sup>, amendments and clarifications are suggested for rules of adoption. However, no changes concerning the current view on applicants' mental and physical disabilities have been made.<sup>96</sup>

**385.** At the beginning of 2010, the newspaper *Stiletan* wrote about the difficulties persons with disabilities have with being accepted as adoptive parents.<sup>97</sup> The article describes a woman with reduced mobility and her husband's attempts to adopt. The couple had adopted a child from China in 2004. Now they wished to adopt a second child. The municipality said no. The presumptive parents themselves put it down to the woman's disability. There is no written account of the reasons for the decision, so the couple has not been able to pursue the case.

**386.** A factor that makes it more difficult is that countries that give up children for adoption, have reinforced their demands on the recipient. China is one of these countries that want to be sure of presumptive adoptive parents' physical and mental health and financial resources.<sup>98</sup>

#### **387. COMMENT**

- Persons with disabilities must have equal opportunities with others to adopt children. Parents' capability of raising children must be judged in the same way as for other parents. If a parent needs personal assistance, an escort or suchlike, or assistive devices, these should be seen as support for parents who care for a child; never as a person who cares for a child instead of its parents.
- The handbook's reference to disability as a reason to avoid placing a child with adoptive parents because they may find it difficult to meet the child's needs, must be eliminated immediately. There are no grounds for this statement.

#### **Support to care for a child**

**388.** Swedish law gives families where one, or more, members have disabilities the right to receive support from society. Support can be given both to parents with disabilities or to parents who have a child with a disability.

**389.** LSS gives, among other things, parents the right to a personal carer, an escort and advice as expert help to families and other next of kin. The legal text does not specifically mention the right to receive support for parenthood. But the law's proposals state that it is the responsibility of social services to intervene with support similar to when parents for other reasons cannot give a child the care it needs.

**390.** The Social Security Act gives family members that are not covered by LSS the right to certain support. For example escorts and some help in the home and support and relief for a person who looks after a close family member who has a disability or is chronically ill. More information about the regulatory framework for assistance is found in article 19.

**391.** There is no comprehensive picture of how those who are covered by the convention do actually have access to the support they need. There are some limited statistics however. The study "our father", about parents with learning difficulties, found that for some, parenthood had worked out. They had received the sort of support they needed to reinforce their ability to care for their children. Others had not managed to cope with the daily responsibility of being a parent and had received help and support to place the child in a family home. Their rights as the child's parents had not been violated. Then there are people who have not received the help and support they need, who have had to leave their children and who feel they no longer have any right to their child.

**392.** Comprehensive studies that focus on support for homes and families have not been implemented. The follow-ups that are carried out concentrate on activities in connection with SOL

and LSS in a more general way. The National Board of Health and Welfare's survey on the living conditions<sup>99</sup> of 57 000 adults with mental disabilities, learning difficulties, autism or reduced mobility found that users' lack of influence over activities on offer, was a reason for their feeling of exclusion and not participating.<sup>100</sup>

### **393. COMMENT**

- All persons with disabilities must receive adequate support to cope with their home and family. Support must be given according to the individual's needs, wishes and family circumstances. An individual's "role" in the family must be taken into account and not coloured by delusions of gender or disability.
- A comprehensive study must be implemented that focuses on the quality and accessibility of the supportive activities that are on offer today to enable individuals to cope with home and family.
- Indicators for regular measurement of accessibility and quality of supportive activities in connection with home and family must be developed.

## **Article 23 3 Children with disabilities and their families**

**394.** Children covered by LSS have, beside the right to counselling and personal assistance, also the right to:

- Stand-in service, which provides help to look after a child with disabilities while the family has a respite.
- Short-term group living, which means that children and young people covered by LSS can stay with another family or at a home with special services for a period of time.
- For information about access to habilitation and rehabilitation see articles 25 and 26.

**395.** Coordinating different activities is essential in order to provide children with adequate information, habilitation and assistive devices. The Swedish Association of the Visually Impaired has pointed out that in some cases children with visual disabilities are not referred by eye specialists to visual centres in good time for families to receive the information, service and support they have a right to. Doctors sometimes wish to wait and see how the child's sight develops. There are also instances when although a child has multiple disabilities, professionals focus on the most obvious one and forget the "lesser" disabilities.

Routines for providing children with support, when and how information is passed on to children and parents, and service and support, differ according to where in the country the family lives. See further articles 19,25 and 26.

### **Sign language for parents – TUFF**

**396.** Regulations for TUFF are found in ordinance (1997:1158) concerning government grants for sign-language training for certain parents. Courses are 240 hours long and provide parents with enough skills to use sign language with their children, thus promoting the child's development. Research shows that parents of children with disabilities often have socio-economic difficulties and are more often subject to burnout than other parents. When a child is born with, or later develops a disability, both the child's and the parent's circumstances are affected. Work life is also affected as are, for example, contacts with pre schools and schools, putting necessary adjustments in place. Hospital visits, investigations, decisions about habilitation plans, monitoring, training, communication courses for coping with communication with the child, take up a lot of time and energy; as does the struggle to obtain a diagnosis that allows access to rights.

#### **398. COMMENT**

- Circumstances for families with children with disabilities must be made easier. We welcome the National Audit Office's ongoing survey of current support for families with disabilities and wish to stress the significance of the disability organisations' experiences and that the proposals that have previously been made concerning solutions are taken into account.
- Those who are responsible for information to parents and children with disabilities should use a checklist to make sure everything is in place and to tick off the dates when the information was given.
- Sign-language training for parents of children who are deaf, deaf blind or hard of hearing is essential for children to "have equal rights within the family" and to develop in the best possible way. 240 hours are not enough to learn a new language. The number of hours needs to increase substantially. Parents must have the time it takes for them to learn sign language.

### **Article 23 4 When a child is separated from his or her parents**

**399.** There are no statistics covering cases where parents with disabilities have been forced to give up caring for their child. Figures show that in 2005 about 20 000 children and young people were subject to some form of being taken into care under the provisions of SOL or LSS<sup>101</sup>. Intellectual disability and lack of care were the reasons for a few of these cases.<sup>102</sup>

### **Article 23 5 Alternative care**

**400.** Children, who, despite various supportive measures, cannot live with their parents, have the right to live with a family or in a home with special services for children and young people. Living with a family means that a child lives with a family other than its own. These placements are voluntary and should be seen, in relation to the child's home, as complementary permanent environments for growing up.

**401.** The Disability Movement's recommendations, see annex 2

## **Article 24 Education**

### **Article 24 2. A Pupils' right to education**

#### **The regulatory framework**

**402.** School is compulsory in Sweden. This means that primary school, classes 1 to 9, are free of charge and compulsory for all children. This includes children with disabilities.

**403.** Sweden has recently passed a new education act that covers all school forms. The law takes effect on January 1, 2011, but will be introduced in three stages with primary school in the middle of 2011. The law weakens both pupils' opportunities to choose schools, and to access support and special pedagogic facilities.

**404.** The non-discrimination act (Lagen om förbud mot discriminering) prohibits discrimination in education. Anyone who feels they are discriminated against can file a complaint to the Discrimination Ombudsman (DO).

#### **405. COMMENT**

- The new Education Act must be reviewed forthwith so that pupils with disabilities receive the support they need in order to be successful at school, and have equal opportunities to choose schools (see item 418.). There is a risk that the new Education Act will lead to pupils having less opportunities than formerly, which we consider inconsistent with Article 24.
- There is effective legislation covering discrimination in schools. Decisions about support and service are recorded in individual plans of action. According to the new Education Act, such

plans can be appealed. This new opportunity to appeal is all well and good, but ineffective as the content of the document that can be appealed is weakened in the process.

### **Statistic comparisons**

**406.** According to Statistics Sweden's (SCB) labour force survey published in 2009, the education level of persons with disabilities is lower than that of the total population, and is most evident among persons with reduced work capacity. In the population, 33 percent have tertiary education, among persons with disabilities without reduced work capacity 28 percent and among persons with reduced work capacity 21 percent. Women with disabilities have tertiary education (27 percent) to a greater extent than men (20 percent).

The comparative percentage of tertiary education for the entire population is 37 percent for women and 30 percent for men.

The number of pupils at primary school who manage a pass in all subjects has increased since the school year 2004/05. In 2007/08, 23 percent of pupils did not reach the pass level in one or more subjects. At the same time, the number of pupils who lack the qualifications for secondary school has increased. In 2008, 88.9 of pupils were qualified to attend secondary school, the lowest percentage since 1998. Statistics for 2009 show a similar number<sup>103</sup>. The Ministry of Education's survey shows that there are small differences between results for boys and girls, for instance girls are slightly better than boys at mathematics. The most substantial discrepancy concerning results is the parents' level of education.

**407.** The Ministry of Education's survey does not show how many of those who do not reach the required level are persons with disabilities. However, there are some supplementary statistics. According to a study from 2001, just half of "pupils with certain neurophysiatic disabilities" were expected to meet the targets set for qualifying subjects. Six years later, this number still corresponded to the one found in a questionnaire carried out by the Autism and Aspergers association in 2007, which showed a 43 percentage of pupils with pass levels in qualifying subjects.

For further information about results, see Article 13 of the alternative report on ICESC. Gender-related statistics in surveys are seldom given in connection with pupils with disabilities.

### **408. COMMENT**

- Considerable measures must be taken so that all children, regardless of abilities and prerequisites, can take part in all compulsory education on equal terms with others and reach the best possible results.
- Gender-related statistics must be presented so that possible discrepancies between boys' and girls' results can be highlighted and reasons for potential differences identified.

### **Absence from school common among children with disabilities on the autism spectrum**

**409.** Although school is compulsory, 59 percent of pupils with Asperger's syndrome are absent from school for longer or shorter periods, according to a membership survey from The National Society of Autism and Asperger. The reasons given are teachers' lack of competence. As many as 20 percent of pupils aged 7 to 9 years have been periodically absent from school. 18 percent of secondary school pupils have been absent for four weeks or more.

### **410. COMMENT**

- Efforts to raise levels of awareness must be made so that teachers acquire the necessary knowledge to teach pupils with diverse abilities and prerequisites.

## Article 24 2. B Inclusive schools

### Regulatory framework

411. Schools, regardless of type, must be open to all pupils, and “A pupil shall be given a place in a school in the municipality and of the child's guardian's choice”<sup>104</sup>. However, the wording of the new Education Act also limits the child's guardian's right to choose schools if the child has a disability. Referring to all schools the Act prescribes:

- “Supplementary grants shall be produced for pupils with considerable need of help and support. The municipality is not obliged to pay supplementary grants for a pupil in need of special support if this would cause the municipality considerable organisational or financial difficulties”
- “The principle organiser is not obliged to receive or offer continued education to a pupil if the municipality has not provided a grant for the pupil”.

### 412. COMMENT

- The new Education Act strengthens pupils' opportunity to choose schools as it gives a guardian the right to appeal a “wrong” school placement. It is therefore, no longer as easy for schools to refuse admission to pupils with disabilities. At the same time, it is now up to the municipality to give grants for the extra resources. If there are no such grants forthcoming, the school can refuse to admit the pupil.
- The provisions in the Education Act must be eliminated so that schools are not permitted to refuse admission to pupils with considerable disabilities. Municipalities and school organisers must be given greater responsibility for the school environment and the content of educational programmes so that schools are suited to the needs of pupils with disabilities.

## Statistical comparisons and research results

*Differentiation – special solutions are becoming more common*

413. The main principle is that primary schools are integrated. But the Ministry of Education's survey from 2009<sup>105</sup>, shows that special groups for pupils in need of support have become more common. Pupils are also put into different groups according to level of knowledge. The Ministry of Education notes that research has shown that solutions such as these can have a stigmatising effect on pupils' self-perception and motivation, and can be detrimental to progress.

### 414. COMMENT

- Pupils with disabilities must always, initially, have support to take part in general education. The random placement now in progress must be considered inconsistent with Article 24. A significant exception are the deaf, pupils hard of hearing and deaf-blind pupils, who must have access to tuition in both Swedish and Swedish sign-language, see further 2.e).

*Inadequate accessibility in schools shuts pupils out*

415. According to a survey<sup>106</sup> from the Ministry of Education, pupils with disabilities do not have the same rights to choose schools as other pupils. One of the main reasons is lack of accessibility to school buildings.

- Every other primary school and four of ten secondary schools lack accessible toilets or lifts.
- Two of three primary schools and half of secondary schools lack automatic door openers.
- For pupils with visual impairments there is often a lack of accessibility accommodations, for example marked level differences are often missing.
- Access to loops and a satisfactory sound environment in class rooms is often missing. Loops are usually only found in pupils' own class room. Many of the teachers who were interviewed say that they are unsure of how to use the technology. Efforts to minimise noise in other school buildings are unsatisfactory.

- Few schools organise regular allergy rounds. In a survey published by The National Board of Housing, Building and Planning (Boverket) and the Swedish Energy Agency (Energimyndigheten), concerning the indoor environment of 131 schools<sup>107</sup>, 80 percent of the schools had moisture damage and two of three had features that could cause substandard quality of air. The Allergy Association often receives reports from members who are severely effected by faulty school environments.

#### **416. COMMENT**

- All sectors of society must continue to conform to the so-called principle of responsibility and financing. Because efforts to render the education system more accessible take time, more efficient measures must be taken to ensure that pupils with disabilities are able to have access to an inclusive school as stated in Article 24.

### **Article 24 2. C Reasonable Accommodation**

**417.** The non-discrimination law bans discrimination in education. The principle organiser of a school, regardless of type or level, is under obligation to provide reasonable accommodation of the individual's requirements. Negligence of this is, in the eye of the law, discrimination.

### **Article 24 2. D Access to necessary support**

**418.** In its survey from 2009, The Ministry of Education notes that primary school results are not going in the right direction. In spite of this, the Swedish parliament confirmed a new Education Act on June 22, 2010 (SFS:2010:800), that does not allow pupils who need special support the same rights as stipulated in the previous Act. The previous Act stated that pupils with special needs were entitled to the support required without specific limitations of targets or results. This right is weaker in the new Act. It stipulates that special support can only be provided up until the pupil has met the targets set by primary school. This could mean for example that special pedagogic support is withdrawn when a pupil reaches the pass level.

#### **419. COMMENT**

- The limitations of the new Education Act must be removed forthwith. All pupils must be able to access support according to their needs, not just up to the pass level.

### **Deficiencies in the teaching environment**

**420.** The Swedish Schools Inspectorate (Skolinspektionen) has viewed secondary school pupils' environment. The review covered 33 schools where there are pupils with visual impairments, hearing loss and mobility disabilities. The review<sup>108</sup> shows that:

- Schools find it difficult to adapt the school environment to pupils' needs.
- Pedagogic accommodations, for example use of alternative methods and technical aids, seldom work satisfactorily.
- The shared responsibility between teacher and assistant is often unclear.
- Most schools do not have buildings that live up to pupils' need of accessibility.

The Ministry of Education is of the opinion that the opportunities inherent in information technology are not efficiently exploited.

**421.** Every school, since 2006, is obliged to put together an Equality Treatment Plan. A survey of the situation at the school, and targeted issues, form the base of the Plan which should be reviewed annually. According to The Ministry of Education, are only ten schools have Equality Treatment Plans that meet the requirements of the law.

#### **422. COMMENT**

- Flaws in the environment at schools must be identified. The Swedish government must ensure that the law's stipulations concerning Equality Treatment Plans are followed.
- Heads of schools must ensure that the Schools Inspectorate's recommendations are followed. To guarantee that recommendations are formulated in the best possible way, the Schools Inspectorate should always cooperate with the disability organisation in question.
- Use of accessible IT technology should increase in schools as this can make the pedagogic situation easier for pupils with disabilities. Increased use, however, must have clear strategies and an on-going pedagogic discussion about the opportunities and limitations of IT technology.

### **Article 24 2. E Special schools and classes for pupils hard of hearing**

**423.** Children hard of hearing and deaf children are found in all types of schools. Of approximately 5000 children and youths from the ages of 6 to 15 years, the majority, 82 percent, attend integrated schools<sup>109</sup>. The integrated school form is often not well suited for the pupils. School organisers, because of inadequate knowledge, do not see pupils' needs, or underestimate them. This is noted in the Schools Inspectorate's review<sup>110</sup>. Pupils who have hearing loss, are deaf or deaf-blind, have access to special schools and classes for those hard of hearing. These schools, with their accommodations, should offer optimal conditions for learning, but their status is fairly low today – municipalities look on them as the last chance for pupils who have "failed". These schools do not always give the pupils support enough to reach the schools objectives. Parents who wish to choose special school solutions for their children, often meet with opposition although they have judged that the child's needs are best served by these schools.

**424.** Inclusive teaching for pupils hard of hearing, the deaf and the deaf-blind, puts great pressure on communication. It is difficult to achieve in large classes, with a teacher who has no special training, and where a pupil's ability to understand speech decides whether he or she learns anything.<sup>111</sup>

#### **425. COMMENT**

- Pupils hard of hearing, deaf pupils and the deaf-blind must be able to choose a school solution that best meets their needs. The options must be equal.
- The Education Act's wording concerning the target group for special schools<sup>112</sup> (and the right to school transport regardless of school) must be changed so that pupils with hearing loss, or no hearing at all, have equal rights to schooling that is effective.
- In order to coordinate society's resources efficiently, there is a need for regional resource centres for persons hard of hearing and the deaf. They should be coordinated at national level.<sup>113</sup>
- The various types of schools must blend so that all people are offered equal education.
- Cooperation among different types of school must be encouraged. Pupils of sign-language must be able to get to know other pupils at other schools.

#### **Special schools**

**426.** A pupil who, due to learning disabilities, is considered incapable of reaching the goals set by primary and secondary schools, has the right to an education at a special school. This applies also to pupils with extensive and lasting intellectual disabilities due to brain damage or who are autistic or have conditions similar to autism. The number of pupils attending special school has increased substantially over the past few years, but varies from municipality to municipality. Many teachers at special schools report that they are teaching children who do not have developmental disorders. The reasons for the increase and its effects on a pupil who is wrongly placed are shown in Article 13 of the disability movement's alternative report on ICESC.

**427.** An ongoing pilot scheme was launched in 1966, where parents are more involved in the education of children with development disorders. The trial run gave a child's guardian the right to refuse the child's participation in compulsory special schooling. In the new Education Act, the pilot scheme is made permanent, but a restriction is included. It states that a child can be placed in compulsory special schooling without the guardian's consent, if there are extraordinary reasons for so doing and in accordance with the school's judgement of what is best for the child.

**428. COMMENT**

- Pupils must be placed in a school and an environment that offers the best possible knowledge-based and social development. Lack of resources at primary school must never lead to the placement of an individual in the wrong type of school.

**The quality of special schools**

**429.** The Schools Inspectorate has reviewed teaching in 28 special primary schools. The survey<sup>114</sup> shows that many schools do not provide pupils with the necessary prerequisites for them to fully develop the abilities as stated in the study programme. Teaching is more concerned with care than with setting challenges that stimulate learning. Deaf pupils, pupils hard of hearing and deaf-blind pupils with learning disabilities also need tuition in Swedish sign language and Swedish

**430. COMMENT**

- Special schools must be better at maximising pupils' academic development and accommodating the tuition to the requirements and needs of the pupils.

**Article 24 3. Practical and Social Skills**

**431.** The Language Act gives the hard of hearing the right to learn, develop and use Swedish sign language. There is, however, no system in place for how this right can be enjoyed.

Children hard of hearing who do not attend special schools, do not have access to sign-language teachers at school. Only special schools can offer children at primary-school age a sign-language environment and tuition in Swedish sign language. Only special schools have teachers with the necessary qualifications to teach sign language to children.

**432.** The right to learn Braille is not included in the Swedish Education Act. Teachers lack the knowledge to teach children reading and writing in Braille.

**433. COMMENT**

- The Education Act must be supplemented with provisions that give pupils the right to learn practical and social skills, like Braille and Swedish sign language, that enable them to take part in education on an equal basis with other members of society.
- Special schools must be open to all persons hard of hearing who wish to learn, develop and use sign language, regardless of whether or not they are expected to get through primary school.

**Article 24 4. The Teachers**

**Teachers' lack of competence**

**434.** The Schools Inspectorate's survey<sup>115</sup> of the situation of pupils with disabilities at secondary school, shows that many teachers feel that they do not have enough knowledge and experience of pupils' disabilities. The Schools Inspectorate also notes<sup>116</sup> that teachers' competence varies among municipalities, among schools within municipalities and within schools. There are 72 to 90 percent qualified teachers in 80 percent of the municipalities. In the suburbs of Stockholm there are a considerable number of teachers who lack university pedagogic training. Free schools, in general, have fewer qualified teachers than municipality schools. In the spring of 2010, the

Swedish parliament agreed on a new teacher training programme, which, right up until the last minute, was criticised by government agencies, independent organisations and experts in the field. The programme lacks necessary components, for example a disability perspective. The government has, however, chosen to implement the reform and ignore the shortcomings.

#### **435. COMMENT**

- All teacher training programmes must be supplemented with the perspective of disability to ensure that pupils with disabilities have access to qualified teachers.
- Schools need to work with their staff's attitudes to ensure that pupils are always treated according to their various needs.
- For pupils who are deaf, hard of hearing or deaf-blind teacher training in Swedish sign language must be secured.

#### **Teachers' lack of knowledge and awareness concerning equal opportunities**

**436.** An official government report, Equal Opportunities in Schools from 2008, (Delegationen för jämställdhet i skolan), notes that progress concerning equal opportunities is slow, and inadequate knowledge and awareness are often the reasons why school leaders, teachers and other staff do not detect gender structures. In June 2008, the government announced a campaign for equal opportunities in schools, in order to promote equality in primary schools and similar school forms, secondary schools and adult education, starting 2008 and ending 2010. Only a third of schools have applied for funds to develop their work with equality.

#### **437. COMMENT**

- All schools must be encouraged to initiate work forthwith for equal opportunities so that gender structures are observed and treated.
- The disability movement wishes to highlight the fact that persons with disabilities are often treated as just that, and not as a girl or a boy, or a woman or a man. It is therefore of importance that when working with equality, there is a perspective of girls, boys, men and women with, and without, disabilities.

## **Article 24 5. Tertiary Education**

### **Adult education**

**438.** Due to shortcomings in primary school education, many pupils with disabilities do not reach a pass level in all subjects. Because of this, access to higher education is very limited. Adults who have not completed primary or secondary education, or who wish to complement their studies, can do so at adult education centres organised by the municipalities, and special programmes for adults. These programmes are for adults with intellectual disabilities. However, in the new Education Act, the government has limited adults' opportunities to study at these schools. One condition for having the right to education at primary level is that a person must "have the ability to comprehend the content of the programme". This wording was previously used only for secondary education.

#### **439. COMMENT**

- No one should be refused a place because of previous shortcomings due to flaws in tuition at primary school. All people make progress must have the right to learn.

### **Folk high schools (liberal adult education)**

**440.** In Sweden so-called folk high schools provide a comprehensive selection of study courses. Further information can be found in the alternative report on economic, social and cultural rights, page 95.

## **Universities and higher education**

**441.** The economic, social and cultural rights of students with disabilities are described in the disability movement's alternative report, Article 13. More recent statistics could not be found. Since January 1, 2009, the non-discrimination law regulates prohibition against discrimination at institutions of higher education. The Act includes an obligation to take reasonable measures of accommodation. Complaints of discrimination are sent to The Board of Appeal for institutions of higher education. There has been a significant increase of complaints. A total of 1542 complaints of discrimination in institutions of higher education were filed in 2009. After the first six months of 2010, 1357 complaints had reached the Board, 233 concerned special support.

**442.** The Disability Movement's recommendations, see annex 2

## **Article 25 Health**

### **Article 25 1. A Health Service**

#### **Regulatory framework**

**443.** The Health and Medical Service Act (HSL) stipulates that the goal of the health service is good health and good healthcare on equal terms for the entire population regardless of place of residence and age. Care shall be given with respect to the individual and according to needs. Cases where an individual feels that he or she has not been given the best possible care, can be reported to The National Board of Health and Welfare (HSAN).

**444.** The non-discrimination law bans discrimination within healthcare. A person who feels discriminated against can report it to the Discrimination Ombudsman.

#### **Statistical comparisons and research results**

##### *State of health*

**445.** The report, "Onödig Ohälsa"<sup>117</sup> (Unnecessary Ill Health), shows that it is ten times more common for persons with disabilities to feel that their health is bad, compared to the rest of the population. Poor mental health and bad dental health are more than twice as common. Bad dental health was most common among persons who lacked savings. 39 percent men and 31 percent women in this group had bad dental health, compared to, respectively, 10 and 8 for the rest of the population. A supplementary report<sup>118</sup> shows that ill health was most common among women and men with mobility impairments, 43 percent men and 32 percent women said their general health was poor. Diabetics, asthma and high blood pressure together with severe bodily pain were more common among people with disabilities than the rest of the population. Severe pain was most common among women and men with restrictions of movement. Less than a third of the interviewees with visual impairments said their health was good.<sup>119</sup>

##### *Unnecessary ill health*

**446.** The report Unnecessary Ill Health<sup>120</sup> shows that much of the ill health among persons with disabilities is caused by lack of influence, financial insecurity and discrimination due to inaccessibility, that is to say, disability factors that lower the quality of life. According to the report, ill health could be reduced by a third if the financial situation improved and people were treated better, together with increased social and physical activity.

#### **447. COMMENT**

- Public health issues must include persons with disabilities more explicitly than hitherto.
- Focus must be put on processes and factors that are disabling, and benefit systems must be adjusted so that ill health due to economy is minimised.

### *Medicine Use*

**448.** The National Board of Health and Welfare (Socialstyrelsen) has investigated medicine use among persons with mental disabilities or autism. The results show that it is more common that these persons are prescribed out-of-date medicines, and that their list of medicines is seldom reviewed. It is also quite remarkable that 20 percent of persons with mental disabilities or autism, use medicines for psychosis and schizophrenics.<sup>121</sup>

In many cases of illnesses, such as heart and lung diseases, kidney failures and neuro-psychiatric conditions, men and women react differently both to medicines and to treatment. Karolinska University Hospital states, however, that there is seldom a gender perspective in medical research.

#### **449. COMMENT**

- All persons, regardless of disability, age or gender must have equal access to adequate healthcare and modern medicine according to their needs and taking into account individual differences.

### *Access to public health services*

**450.** The National Board of Health and Welfare has made a survey<sup>122</sup> of Swedish general practitioners' surgeries and social services offices to test accessibility for persons with disabilities. The Board says: "Many social services offices and healthcare centres do not have nearly enough accessibility and it is hard for persons with disabilities to seek care or support. People run the risk of being totally excluded." The report found that for persons with mobility impairments access is relatively satisfactory. It is significantly worse for persons with communication difficulties, such as visual impairments or hearing loss. The staff at health centres have no knowledge of sign language and deaf persons. There are often no text telephones or videophones. It should be possible to install these in hospital wards when there is a need.

#### **451. COMMENT**

- Negligence to take measures for accessibility must be judged by law as discrimination. For further information, see Article 9.

## **Article 25 1.B Health services needed by persons with disabilities specifically because of their disabilities**

**452.** There are not enough specialists in allergies, neither for children nor for adults. Most of those practising today will soon be retiring and new recruitment does not match the need. There is a similar tendency among skin specialists. The quality of care varies around the country and is unequal. One example is the allergy vaccination, which is much more common in Halland than in Gävleborg. Healthcare centres with special asthma clinics discover early cases of asthma and chronic obstruction of the lungs and can stop the disease developing, thus creating a better quality of life for the patient. There are not enough of these clinics. There are no routines for the early identification of hearing loss in adults. Adult education, especially "Swedish for Foreigners" SFI, completely lacks routines for the identification of hearing loss. In the working environment, employees are checked only at places of work where there is deafening noise. Workplace noise can cause health problems even when the noise levels are below average, but there is no demand for hearing tests in these environments.

#### **453. COMMENT**

- Close cooperation between primary healthcare, other healthcare facilities and specialist clinics for asthma and allergies must be encouraged. The so-called allergy centres can work as consultants and be of assistance in training courses.

- Routines for hearing tests at workplaces and in adult education are needed, especially for SFI students.

### **Older persons and disabilities**

**454.** Older persons with hearing losses who do not receive adequate care, risk becoming isolated if they are not stimulated by chatting and social interaction. This has been shown to lead to depression and pseudo dementia, and can accelerate the development of dementia diseases. Older deaf persons need better access to communication by sign language at healthcare centres, homes for the elderly or in connection with services for the elderly.

#### **455. COMMENT**

- The different players in the healthcare sector must have knowledge of the interpreter service provided, so that deaf and deaf-blind persons have access to communication, regardless of the care organiser. Older deaf persons must be offered care in environments with access to sign language. Also, deaf persons who have dementia, need care in similar environments.

## **Article 25 1.E Health Insurance and Life Insurance**

**456.** The non-discrimination law bans discrimination within the field of insurance. Despite this, it is common for persons with disabilities to be totally denied the right to take out policies for illness, accidents and life insurance. For others, policies are more expensive. A health declaration is needed when applying for insurance for children, for illness or for accidents. The declaration contains questions covering illnesses, disabilities, smoking and weight.

A health declaration is required to enable the insurance company to assess the risk before accepting the application. In 2010, many cases have been appealed to the Discrimination Ombudsman. For example, a deaf woman who was denied taking out an accident policy because of reduced work capacity. Another case concerned a boy who was denied taking out any health insurance because he was hard of hearing. The insurance company Trygg Hansa has the right to deny the parent to take out an insurance.

#### **457. COMMENT**

- If the Stockholm District Court's decision, that it was not discrimination when Trygg Hansa denied the boy sickness insurance because he was hard of hearing gains legal force, the law must be revised and amended. No person shall be denied an insurance policy because she or he has a functional disability.

**458.** The Disability Movement's recommendations, see annex 2

## **Article 26 Habilitation and Rehabilitation**

### **Article 26 1. Access to habilitation and rehabilitation**

#### **Regulatory framework**

**459.** Several players are responsible for habilitation and rehabilitation. Medical rehabilitation is the responsibility of the healthcare services, social rehabilitation rests with municipalities and rehabilitation for the labour market is the responsibility of The Social Insurance Office and The Employment Office. The Health and Medical Service Act (Hälsa och sjukvårdslagen) stipulates that county councils should provide their residents with habilitation, rehabilitation, technical aids and interpretation service.

## **Statistical comparisons and research results**

**460.** Because county councils' account and management systems do not include rehabilitation and habilitation, follow-up of access and quality is not satisfactory. Nevertheless, there is limited information:

- The National Board of Health and Welfare (Socialstyrelsen) has monitored the need for rehabilitation and estimates that approximately 60 percent receive the treatment they need<sup>123</sup>.
- The National Board of Health and Welfare is not able to assess whether access to habilitation and rehabilitation for persons subject to LSS is sufficient. The Board can state, however, that it is altogether difficult for this target group to have their needs provided for. They find it difficult to access coordinated facilities from healthcare, social services and rehabilitation. Lack of continuity and limitations of how an individual is able to describe his or her problem are also part of the picture. Of the third who answered the questionnaire, many say that they are not satisfied with the rehabilitation or habilitation they have received<sup>124</sup>.
- Handu's study<sup>125</sup> of living conditions among deaf-blind persons, shows that a sixth of those who answered do not have an individual rehabilitation plan or have one that they are not satisfied with.
- The Swedish Association of the Visually Impaired (Synskadades Riksförbund) open comparison of county councils' rehabilitation, shows substantial variations in the amounts invested in rehabilitation. SRF also notes that many visually impaired persons do not receive rehabilitation to meet their needs and that enables them to live independently, partaking fully in society.
- The Swedish Association of Hard of Hearing People (Hörselskadades Riksförbund) has in eight reports from 1998 to 2009, presented various open comparisons of hearing healthcare. The reports show that variations in the quality of healthcare remain all over the country.

### **461. COMMENT**

- The Act stipulates that society is obliged to offer persons with disabilities habilitation and rehabilitation. Municipalities and county councils are responsible for coordinating facilities and for initiating their own routines and principles for rehabilitation activities. This leads to variations in the kind of rehabilitation or habilitation that is available to a person. National guidelines must be created, which aim at guaranteeing equal rehabilitation and habilitation regardless of where a person lives.

## **Article 26 1. A Begin habilitation and rehabilitation at an Early Stage**

**462.** Because there are no follow-up systems for habilitation and rehabilitation, we do not know in general, whether or not efforts start at an early stage. Some federations of persons with disability, however, point out that:

- Persons with autism or Aspergers syndrome, still have difficulties in accessing necessary rehabilitation. The situation is most critical for those who are diagnosed as adults.
- For persons with mobility disabilities, it is pointed out that the rehabilitation given in connection with an acute condition is better than the opportunities available to persons in need of "recurrent" rehabilitation.
- Children who are born with heart deficiencies but no other disabilities, do not, generally speaking, have access to necessary habilitation and rehabilitation, although this is regulated in The National Guidelines, 2008 (Nationella riktlinjer).
- Persons with mental ill health often lack opportunities of habilitation or rehabilitation. When such opportunities are eventually provided, individuals are often sent far away from their homes, and feel as though they are placed under supervision.

#### **463. COMMENT**

- If we are to know whether habilitation and rehabilitation begin at an early stage, and to be able to develop and improve activities, county councils' account and management systems must include rehabilitation and habilitation activities for women, men, girls and boys with disabilities.

### **Article 26 1 B. Rehabilitation Close to Communities**

**464.** Coordinating responsibility for rehabilitation and habilitation lies with municipality healthcare centres and county councils' primary healthcare. This means that rehabilitation and habilitation must be provided as close as possible to the patient's own community. What cannot be provided at this level, is catered for at council or regional level.

### **Article 26 2. Expert knowledge**

**465.** The disability movement wishes to stress that knowledge about the needs and situation of deaf persons, the deaf-blind and persons hard of hearing, has deteriorated. Specialists in the field (teachers, technicians and audiologists) are hard to find, and their expertise is disappearing along with retirement. Audiology as a field of expertise has been replaced by branch courses for ear, nose, and throat specialists. The demand for specialists, especially those with teaching abilities, has decreased both in municipalities and in hearing care. Instead, many municipalities try to solve the competence problem by employing general competence. There is also a need of targeted training in sign language and deafness for hearing care consultants and CI teams.<sup>126</sup>

#### **466. COMMENT**

- Multidisciplinary specialist competence in audiology must be guaranteed so that high quality hearing care is available.
- Knowledge of sign language, and its use for persons hard of hearing, and in-depth knowledge about hearing loss and deafness, must increase in CI teams and among hearing-care consultants.

### **Article 26 3. Assistive Devices and Technology**

#### **Regulatory framework**

**467.** County councils and municipalities are, under The Health and Medical Service Act (HSL §3b and §18b respectively), obliged to provide assistive devices and technology. Individual healthcare organisers, however, decide which products their unit can provide as personal assistive devices.

#### **Statistical comparison and research results**

##### *Variations in the supply of assistive devices and technology*

**468.** In The Swedish disability movement's project "Assistive devices and technology are indispensable for participation and good quality of life", there is a survey on the distribution of assistive devices in Sweden. The results show that the regulatory framework differs among county councils and municipalities. More and more devices are seen as the individual's responsibility, the user pays for, and buys the product at ordinary shops. Referring to individual responsibility has become, in many cases, a way of rationing different assistive devices. Another viewpoint is that assistive devices that do not require healthcare professionals' help to fit out, are classified as self care products. The survey shows that all regions and county councils charge a fee for assistive devices. The fees vary considerably among the regions and are charged either for the whole cost, or part of the cost, of the device. Costs vary also depending on the type of device. Furthermore, there are variations of fees charged for appointments, for fitting sessions, for renting

and more. The project states that “dissimilarities around the country are twice the number of similarities”.

#### Supply of assistive devices and technology

- **469.** Only 10 of the 20 county councils that answered the question, grant assistive devices to persons over 18 years of age who have documented problems with reading and writing/dyslexia. (Three counties answered that they are presently looking into the matter of assistive devices and target groups.)<sup>127</sup>
- Only 11 of 20 county councils said that they are investigating the frequency of reading and writing problems in children under 18 years old.
- Handu's survey<sup>128</sup> of living conditions among persons who are deaf-blind, shows that approximately a third of all those who answered, are missing one or more of the assistive devices they need to compensate their visual impairments and/or hearing loss. More men than women have two hearing aids. There are considerable differences in the amount persons hard of hearing pay for their hearing aids and assistive devices<sup>129</sup>
- It is common that persons with cognitive disabilities do not receive the devices they need although development in the field of cognition has progressed. One reason for this seems to be, that society and doctors do not have the required knowledge about cognitive disabilities and cognitive assistive devices.<sup>130</sup>

#### **470. COMMENT**

- National regulatory frameworks for the assistive devices sector must be produced in order to rectify the variations. The individual's need of assistive devices and technology must be the decisive factor, and needs must be met without extra cost for the individual.
- Users and guardians must always know which devices are available. Individuals cannot be expected to discover this before they can discuss with a doctor.

**471.** The Disability Movement's recommendations, see annex 2

## **Article 27 Work and Employment**

### **Article 27 1. A Discrimination on the labour market**

#### **Regulatory framework**

**472.** The non-discrimination law bans discrimination on the basis of disability in all areas of labour, including job seekers, employees and those seeking or undergoing traineeships. When hiring people, dealing with career advancements or in connection with training courses, an employer is obliged to take reasonable measures to support or accommodate persons with disabilities, so that they can partake on an equal basis with others. An employer who does not take heed of this is guilty of discrimination.

A person who feels that he or she has been discriminated against, can report the case to The Equality Ombudsman, DO. The number of reported cases has increased by 20 percent during the first six months of 2010, compared to the first six months of 2009.

#### **Case Law**

**473.** The case AD 13/10, number A 59/08, 2010-02-17, referred to the non-discrimination law. However, the Labour Court concluded that it was not discrimination when The Social Insurance Office refused to employ a woman as a researcher, saying that it was not possible to adapt a computer programme to Braille. The woman applied for the job as a researcher at The Social Insurance Office. When she was interviewed, she explained that there are assistive devices and how problems can be solved.

She did not get the job, although she had all the required qualifications and good references. The Social Insurance Office did not believe that the internal computer programme could be used when

adapted to Braille. The Labour Court found that The Social Insurance Office was under no obligation to adapt the programme to Braille, which had to be undertaken if the woman was to manage the job of researcher.

#### **474. COMMENT**

- The disability movement is very critical of the Labour Court's interpretation of the law. We feel that the Social Insurance Office, being a public employer, should render both its internal and external activities accessible. If the wording in Article 9, together with the principles of universal design, had been applied when procuring the computer system, the woman with visual impairment could have worked at The Social Insurance Office.<sup>131</sup>

### **Statistical comparisons and research results**

#### *Employees with disabilities*

**475.** Although the Labour Law protects people against discrimination, there are considerable differences in levels of employment and participation in the labour force. In Statistics Sweden's (SCB) labour force survey for 2009<sup>132</sup>, 13 percent of the population in work and employment say they have some form of disability. 7 percent of these reported reduced work capacity. More women than men say they have a disability; and more women than men report reduced work capacity.

In the age group 50 to 60 years old, almost half are persons with disabilities, and over half of them have reduced work capacity.

#### *Participation in the labour force – labour force rate*

**476.** In 2008, 66 percent of persons with disabilities were included in the labour force compared to 79 percent for the entire population and 81 percent for persons without disabilities. Among persons whose labour force is reduced, 55 percent take part in the labour force.<sup>133</sup>

**477.** In 2004, the labour force rate for persons with disabilities was 65 percent and in 2006, 62 percent.

The National Board of Health and Welfare's (Socialstyrelsen) survey on living conditions<sup>134</sup> of 57,500 persons with mental disabilities, learning disabilities, autism or mobility disabilities, found that only 10 percent of this group have a connection with the labour market.

Further statistic comparisons are given in the disability movement's alternative report on ICESC, Article 6, page 22.

#### *Unemployment*

**478.** Unemployment for persons with disabilities was 6,5 percent in the fourth quarter of 2008, compared to 4,9 percent for the total population.<sup>135</sup> Among persons with reduced labour force, 9,1 percent were unemployed. In 2006, 6,3 percent persons with disabilities were unemployed (5,1 percent for the entire population). Comparative statistics for persons with reduced labour are not available.

#### *Young employees*

**479.** Young people with inherent disabilities, or disabilities acquired at an early age, are especially vulnerable. Statistics Sweden's (SCB) labour force survey from 2007, shows that unemployment among youths has, in general, decreased. The disability movement notes, however, that the number of early retirements among the youngest, persons between the ages of 19 to 29 years, is increasing, and it is in this group that the increase of early retirements is largest.<sup>136</sup> Over the past few years, the number of persons of 22 years of age or younger, involved in daily activities, has increased dramatically. The increase is said to be caused by a tougher labour market and slimmer chances of getting a job. In over half of the country's municipalities, very few persons go from daily activities to open employment.<sup>137</sup>

#### **480. COMMENT**

- Sweden must take measures that lead to considerably more youths with disabilities finding jobs than is the case today.
- Trial activities where job centres and schools work together have shown good results
- The municipalities should be more active and, together with job centres, provide jobs that are suited to persons who have recovered, or are on the way to recovering, from mental ill health.

#### *Perceived discrimination among persons with disabilities*

**481.** Statistics Sweden's (SCB) labour force survey<sup>138</sup>, shows that 12 percent of those with disabilities who answered, had felt discriminated against in some way because of their disability. Many more, 22 percent, of those in work with reduced labour force participation, felt discriminated against. Four percent of persons with disabilities, and six percent of persons with reduced labour force participation, have at some time during the past five years, felt that, because of their disability, they did not get the job they had applied for, although they were fully qualified. Approximately half of persons with disabilities have not felt discriminated against, and 34 percent say that they have not applied for a job during the past five years. Four percent of those in work with reduced labour force participation, say that they had been passed by when they sought advancement.

#### **482. COMMENT**

- The non-discrimination law bans discrimination on the basis of disability. Persons with disabilities must be informed of the right to report cases of discrimination.

## **Article 27 1. B Conditions of Work**

### **Regulatory frameworks**

**483.** Persons with disabilities are subject to the same labour laws as everyone else and have, thus, according to the law, the same right to safe and healthy working conditions, equal remuneration for work of equal value and redress of grievances.

**484.** Text under this item is removed because the legal framework has changed.

#### **485. COMMENT**

- The wording of the Employment Service's directives must be removed forthwith. A person in work must receive necessary support regardless of age.

### **Statistical comparisons – different wage determination**

**486.** Although there are principles ensuring equal wage for work of equal value, and laws prohibiting wage discrimination, differences in wage determination do occur. Six percent of persons with reduced labour force participation, and approximately one percent of persons with disabilities but full labour force participation, say that they have, due to their disability, at some point during the past five years, been prejudiced against when wages were determined. Women report wage discrimination more than men. Wage structures and differences between men's and women's wages have been examined in other UN bodies (ESC, UPR and CEDAW). In all cases, Sweden has been criticised for the differences in wages between men and women. These differences are also clear in the disability movement.<sup>139</sup>

#### **487. COMMENT**

- All types of wage discrimination are unacceptable. Measures to prevent differences in wages among persons with and without disabilities, and between men and women, with and without disabilities, must be taken and used.

## **Article 27 1. C Exercising Labour and Trade Union Rights**

### **Regulatory framework**

**488.** Several laws and decrees regulate the individual's right to support in connection with work. For further information, see the government's report.

The regulatory framework's wording, is, generally speaking, good. There are, however, some target groups and areas that do not have the right to support. Individuals do not have the right to assistive devices that enable them to seek jobs. (If an employee and an employer cannot communicate with each other because they have no technical hearing devices, the chances of getting a job are slim)

### **Handling and shared responsibility**

**489.** There are many different activities available, depending on the situation one finds oneself in. However, the disability movement's feeling is, that it is difficult, both for the individual and for the employer to grasp the overall range. It is difficult to understand the difference between what is counted as an assistive device for work and an assistive device for healthcare. The regulations concerning persons who need interpreters at work, for example, are very complicated. The County Council, The Employment Service and the employer are all responsible for payments and this creates ill will and uncertainty as to who is responsible for the different costs. In its draft budget for 2011-2013, The Employment Service has asked the government to launch an official inquiry into the possibility that all types of interpreters can be administrated from one agency.

### **490. COMMENT**

- Basic support connected to disability and special support connected to work, should be administered by the same authority. The present division among different players makes it more difficult to access necessary support.
- A universal telephone number for information about all labour market activities should be introduced. This would facilitate information about, and handling of, activities connected to work.
- It is desirable that there be only one authority that is responsible for payments in connection with communication and technical hearing devices and writing and sign language interpreters.
- Employers cannot be responsible for the cost of interpreters as this would directly have an effect on the competitiveness of deaf persons, the deaf-blind and persons hard of hearing, on the labour market.
- Officials' knowledge about different disabilities, about matters related to disability and about legislators' intentions are essential if the individual is to receive the best possible support to earn a living.
- As responsibility now lies with the local job centre, it is of the utmost importance that the relevant knowledge is still available.
- It is unacceptable that The Employment Service sees certain disabilities/diagnoses, for example deafness, as equivalent to having reduced work capacity. The handling must always emanate from an individual's abilities and prerequisites, not from a preconceived idea that disability is equivalent to having reduced work capacity.

### **Statistical comparisons and research results**

**491.** In Statistic Sweden's (SCB) work force survey<sup>140</sup> from 2009, nearly three quarters of those employed with disabilities said that they are in need of some adjustments to the working environment. Women need adjustments more than men. Most said they receive help when they need it. The main accommodations are needed for work tasks, the pace of work and the working hours (especially women) and/or assistive devices.

#### **492.COMMENT**

- Persons who work at places where current regulations are followed, have access to all necessary support.

#### **Union Rights**

**493.** In Sweden, all people have the right to exercise their labour and union rights. Inadequate access to union premises and activities, however, makes it difficult for persons with disabilities to become involved in union matters.

#### **494. COMMENT**

- Unions must be encouraged to make their information and activities accessible to persons with diverse disabilities.

### **Article 27 1. D Vocational guidance and placement services**

**498.** Article 6 of the alternative report on ICESC, highlights substantial flaws in vocational counselling and placement services. For example, both educational and vocational guidance still focus on the individual's limitations instead of on his or her knowledge, ability and ambitions

#### **496. COMMENT**

- It is important, especially for young people, that they are not confronted with attitudes that limit their selfidentity.
- Persons who acquire a disability at a working age have a greater need of comprehensive guidance.
- A comprehensive programme to raise the competence of vocational counsellors and placement officers should be implemented. The content of the programme should be decided in collaboration with the disability movement, and focus primarily on raising awareness of the prerequisites of persons with disabilities, rather than knowledge of various diagnoses.

### **Article 27 1. E Promote Employment Opportunities**

#### **Attitudes on the labour market**

**497.** In a questionnaire from 2009, The Employment Service asked 12,500 private and public employers if they would consider offering persons with disabilities working experience or work training or, alternatively, employment. 40 percent of the private employers said yes, 35 percent no and 25 percent had no opinion. The comparative rate for public employers was 50 percent yes, 14 percent no and 36 percent no opinion.

**498.** To gain more information about employers' attitudes, Samhall sent a questionnaire<sup>141</sup> to 300 businesses. The most common answers to the question "What would persuade you to consider employing persons with disabilities next time you need to recruit?" were:

1. We would employ a person with disability with the right competence(23)
2. Financial support for adjustments needed at the work place (17)
3. A trial period before employment(14)
4. Financial support, for example subsidised wage or tax relief(14)
5. Assistance in finding the right person for the job (12)

#### **499. COMMENT**

- The support that the employers wish for is available today in Sweden. Their inadequate knowledge about these programmes must be resolved. If activities that are specially targeted at employers and persons with disabilities are to succeed, negative attitudes about persons with

disabilities must change, among the players on the labour market, in legislation, among persons with disabilities and in society as a whole.

### **General inaccessibility leads to unemployment**

**500.** According to the law that bans discrimination, an employer is obliged to provide reasonable accommodation at the workplace. To enable persons with disabilities to choose work on equal terms with others, however, the wider society must be more accessible.

#### **501. COMMENT**

- The legal obligation to make workplaces accessible, comes into force as soon as a decision about work or training has been made. If persons with disabilities are to be included in society and find jobs on the open labour market, the disability perspective must be embedded in all contexts.
- The disability movement wishes to refer to the court case, and the comment, in article 27.1a (item 473) and stress, that failure to take a disability perspective leads to unnecessary unemployment.
- Failure to take measures for accessibility must be judged by law as discrimination!

### **Unsafe working environments make it difficult to keep a job**

**502.** If people are to keep their jobs and enjoy safe and healthy working conditions, more attention must be paid to management of risk factors. Some examples are materials that cause allergies and noise disturbance at work. Today's practice of the environmental law, for example, aims to prevent employees becoming hard of hearing. However there are no national standards or limits for noise disturbance, noise that makes it difficult to hear what others are saying or that effects memory or concentration.

Regulations for the plans of the workplace lack explicit guidelines about allergy-related factors. An example are regulations about the use of mats and textiles.

#### **503. COMMENT**

- National standards and limits for noise disturbance are needed. The regulations for how a workplace is planned must be reviewed. Employers need more explicit guidance in order to create workplaces for persons with diverse disabilities. Research into the reasons why workplace accidents occur must be promoted.

## **Article 27 1. F Self-Employment**

### **The regulatory framework**

**504.** There is general financial support for persons who wish to start their own business, and targeted support for persons with disabilities who wish to do the same. The disability movement has no opinions on this subject, referring instead to the government report.

### **Statistic comparisons and research result**

**505.** Approximately one in ten persons is self-employed, this applies both to the population as a whole and to persons with disabilities. It is even more common among persons with reduced work capacity. Men outnumber women as self-employed, both in the population as a whole and among persons with disabilities.

#### **506. COMMENT**

- Persons with disabilities can receive financial support to start their own businesses. The regulations concerning support given to run a business must be revised, so as to include compensation for extra costs because of disability, regardless of which type. Persons hard of hearing, the deaf and deaf-blind, who run their own businesses, pay most of the costs for interpretation themselves, which rules out competitiveness on equal terms.

## **Article 27 1. G and H Employment in the Public and Private Sectors**

**507.** The dominating place of employment for persons with or without disabilities, is the private sector. Statistic Sweden's (SCB) work force survey from 2009, shows that persons with disabilities work for local public authorities more often than the rest of the population. This applies especially to persons with reduced work capacity. In the central public sector, however, the rate of persons with disabilities is lower than persons without disabilities (4,9 percent compared to 5,3 percent).

Men work to a higher degree than women in the private sector, while the opposite is true for municipalities and county councils. This applies to persons both with and without disabilities. Persons with disabilities work, to a higher degree than persons without, in the service sector, in care, in sales, as machine operators/process technicians and in transport and in jobs that do not ask for special vocational training. A small number of persons with disabilities, compared to those without, are found in executive/leader positions and in posts where professional knowledge or higher education is required.

### **508. COMMENT**

- The government sector as a whole, should be encouraged to show an example and employ more persons with disabilities.

## **Article 27 1. J Employment on the Open and Sheltered Labour Markets**

### **The labour market**

#### **Targeted activities**

**509.** In Sweden, there are various means of easing persons with disabilities into employment on the open market. For example wage subsidised jobs, special support for introductions to a workplace and follow-up later, and subsidised activities for work training .Other labour market activities are also open to persons with disabilities. For further information about different measures, see the government's report.

### **510. COMMENT**

- The disability movement welcomes these targeted activities but we think that much more can be done to help persons with disabilities secure jobs. Accessibility in general, in the whole of society must improve significantly. And negative attitudes must be tackled if the targets are to be met.
- Because education is often a precondition for work, schools must be available. The school system is in great need of renovation, see further Article 24.

#### **Daily activities**

**511.** According to the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), persons with learning disabilities, autism or similar disorders, and persons with massive and permanent intellectual disabilities or adult brain damage, have the right to “daily activities”.

**512.** A national survey shows that the range of activities is considerable. It is, however, difficult for municipalities to find activities to suit all. The challenge is to develop the content and structure of daily activities and also to find ways to employment. In more than half of the country's municipalities<sup>142</sup> very few leave daily activities for work.

### **513. COMMENT**

- Special targeted activities must be designed to facilitate the transition to employment.

### **Sheltered employment in the public sector**

**514.** Sheltered employment in the public sector aims at giving persons with disabilities the chance of employment combined with rehabilitation. In the long run, the job should lead to employment on the open labour market. Three groups are given priority: persons with psychiatric disabilities, persons with intellectual disabilities or neuropsychiatric disabilities and persons with multiple disabilities.

It is the task of Samhall AB to implement this labour market policy. The jobs Samhall offers are tailored to the needs and abilities of the individual. The commodities and services Samhall produces are sold on the market thus making the work meaningful. The Employment Service has the exclusive right to allocate these sheltered Samhall jobs to persons with disabilities. Samhall and the government sign a contract that regulates Samhall's responsibilities. The Swedish National Audit Office (Riksrevisionen) has screened the Employment Service's allocation of jobs, Samhall's activities and the government's leadership. The survey shows that both Samhall and the Employment Service follow the assignment. (5,4 percent of Samhall's personnel, 1029 persons had in 2009, been recruited by other employers. The goal was 5 percent). However, the number of women who left Samhall for other jobs has not increased and Samhall has done nothing to see that it does. The survey shows that there is scope for the government to lift the target levels.

#### **515. COMMENT**

- The government should raise target levels for Samhall's activities so that more persons with disabilities find work on the open labour market.

### **Article 27 1. K Vocational Rehabilitation**

**516.** In Sweden, vocational rehabilitation is an important issue, for The Employment Service, for The Social Insurance Office and for employers. The Advisory Board for Rehabilitation's (Rehabiliteringsrådet) report<sup>143</sup> from 2010, shows that vocational rehabilitation is most effective when activities are introduced during the first two months of sick leave. The report shows that the majority of those who were rehabilitated at an early stage did not take sick leave. Among those who were wholly or partly on sick leave from their jobs, only ten percent had taken part in activities within the framework of the so-called rehabilitation guarantee. The Advisory Board for Rehabilitation notes on page 13 that "If just 10 percent of those on sick leave were rehabilitated, there must be many who have not received the help they are entitled to."

Officials' knowledge about certain disabilities, chronic diseases and allergic diseases and their implications and suitable methods of treatment and adjustments at workplaces, is often inadequate. This makes returning to work difficult. The new and stringent regulations for health insurance (which are described in Article 28) demand that the individual's ability is tested against the entire labour market after the 181<sup>th</sup> day of sick leave. Inadequate knowledge about suitable rehabilitation activities and adjustments at workplaces lowers the chances of the individual on the labour market. If a person does not accept a job offer, his or her insurance is revoked, regardless of whether rehabilitation has taken place.

#### **517. COMMENT**

- The Social Insurance Office must ensure that rehabilitation on an individual basis always takes place within 2 months of the first day of sick leave. Sick leave is based on medical grounds and the disability movement would therefore like to emphasise that medical rehabilitation must come before rehabilitation for work.
- If rehabilitation for work involves retraining or any kind of study course, the practical preconditions, and the costs, must be provided without delay.

- The Social Insurance Office, employment offices and players in the education sector must work together more closely so that rehabilitating activities that enable a person to return to work are coordinated or overlap without delay.
- Social Insurance Office officials, and others, need more knowledge about the ramifications of chronic diseases and allergy diseases, and about suitable methods of treatment.

## **Article 27 2. Slavery and Forced Labour**

**518.** The government report, (SOU 2004:71) on sexual exploitation of children and people trafficking in Sweden, emphasises that alienation, lack of parental care and protection together with childhood abuse cause an increased risk of being drawn into commercial sexual exploitation. In the alternative report, articles 7, 8 and 23, on ICCPR, it is shown that various forms of abuse are more common among children with disabilities, and that parents, especially those with intellectual disabilities, do not always receive the support they need to give their children a safe upbringing. This means that persons with disabilities and their children, are an especially vulnerable group, and that there is a risk that they can be used for commercial sexual exploitation. There are no recent statistics. In 2010, however, the media have reported that several women with learning difficulties have been encouraged, and finally forced, to sell sexual services. More information and the disability movement's recommendations, can be found in article 8, in the alternative report on ICCPR.

**519.** The Disability Movement's recommendations, see annex 2

## **Article 28 Adequate Standard of Living and Social Protection**

### **Article 28 1. The right to an adequate standard of living**

#### **Regulatory framework**

**520.** A person who is not capable of satisfying his or her own needs and has no other means of doing so, is, according to The Social Services Act, entitled to benefit from the municipality's social services for sustenance and life in general.

There are also special financial and social support programmes for persons with disabilities. For further information, see Article 28 c.

**521.** The Anti-discrimination Act bans discrimination due to disability in connection with housing and within the framework of the social insurance system.

**522.** Several laws covering support and service for individuals with disabilities have a limit of 65 years of age. To have a disability often means higher costs and more need of help. The individual can claim compensation for the use of a car, for assistive devices at work and for personal assistance, among other things. A person who requires a disability after the age of 65, however, is not entitled to these compensations.

#### **523. COMMENT**

- Sweden's regulations for social and economic support to individuals are, basically, good. There are inadequacies, however, in the practical implementation of the laws, see under article 28 2a, b and c.
- All age limits in social services and social insurance must be erased. Need and not age must be decisive for all types of compensation and activities.

## Statistical comparisons and research results

### *Economics*

**524.** The National Board of Health and Welfare's (Socialstyrelsen) survey of living conditions<sup>144</sup> among 57,000 adults with psychiatric disabilities, learning disabilities, autism or mobility disabilities, shows that persons' with disabilities living conditions are significantly worse than average. Their economy is bad, their education levels are lower and they are not firmly established on the labour market. The results show that persons with these disabilities often have a small sum left when tax has been deducted from their wage and benefits. This group had, on average, roughly 100,000 SEK a year to live on. The average for the population as a whole is 189,000 SEK.<sup>145</sup> The low incomes are mainly due to the fact that most people in this group are dependent on health insurance and labour market subsidies together with benefits. Only 10 percent of those who participated in the survey have jobs. One group is highlighted as especially vulnerable – persons with psychiatric disabilities, aged 20 to 30 years, who often live on benefits. A Survey of Public Health (Folkhälsoundersökning)<sup>146</sup> shows that because of inadequate everyday service, worry and anxiety are more common among persons with visual impairments than in the population as a whole. Mostly, the reasons for inadequate service are decisions made by officials, not needs and wishes of the individual.

### **525. COMMENT**

- Not being able to afford to live like everyone else has social implications. Bad economy effects many aspects of life such as health, housing and leisure time. Inadequate, much needed support for daily living creates unnecessary ill health. Suggestions for measures to be taken, see item 530 below and Article 19, items 312-318.

### *Housing and homelessness*

#### Housing for persons with asthma and allergies

**526.** The Environmental Code (Miljöbalken) stipulates that keeping houses in a healthy condition is the responsibility of the landlords. An environmental survey shows that 18 percent have some form of moisture damage in their homes. 7 percent<sup>147</sup> say that the indoor environment has a negative effect on their health. In some cases it takes so long to get something done by the officials, that persons must move because they become too ill to stay and wait for adjustments to their indoor environment.

#### Housing for persons who are electro hypersensitive

**527.** The Swedish Association for the Electro Sensitive (Elöverkänsligas förbund) carried out a survey among its members in the spring of 2005. The survey shows that 35 percent of the Association's members had been forced to leave their homes because of electromagnetic radiation and because they could not afford to pay for decontamination.<sup>148</sup> There are no recent surveys, but the cost of decontaminating homes from electromagnetic radiation remains. The Association still receives calls from persons who are electro hypersensitive and who are living in tents and huts with no access to clean water or acceptable living conditions.

### **528. COMMENT**

- The Environmental Code and its regulations must be supplemented in order to allow for better opportunities for persons with diverse hypersensitivities to stay in their homes. (see further Article 9)
- Measures must be taken to support those groups of persons with disabilities who are at risk of becoming homeless. For example, persons who are electro hypersensitive must be entitled to support to have their homes decontaminated.
- There is a need for areas of low radiation to serve as temporary solutions in cases of acute evacuation and rehabilitation of electro hypersensitive persons.

## **Article 28 2. A Poverty**

**529.** Persons with extensive disabilities are often those with the lowest health insurance because they have not had work and an income. They have to make do with the health insurance's guarantee benefit. In 2009 this amounted to 102,720 SEK per annum, that is to say 8,650 SEK per month. Added to this, rents for homes with special service as described in the Act Concerning Support and Service for Persons with Certain Functional Impairments(LSS) are very high. The reason for this is that the municipalities that provide these homes charge fees for facilities that are supposed to be provided free of charge. The government bill concerning LSS, states that persons shall not be held liable to extra costs caused by their disabilities. This principle is often disregarded as municipalities charge persons who live in homes with special services extra rent for facilities they are entitled to. Low income and high rents often lead to people with extensive disabilities living in extreme poverty.

### **530. COMMENT**

- Persons who are considered to have such severe disability that they cannot work are few. It is insecure and illogical that economic support intended as an insurance against temporary interruptions of work, is allotted to individuals who have no possibility of participating in working life.

## **Article 28 2. B Security Systems**

### **Sickness benefit cuts**

**531.** In 2008 new rules were incorporated into the health insurance system. The most significant change is the introduction of a time limit for how long The Social Insurance Office (Försäkringskassan) pays sickness benefit. There were no such limits previously. The time limit for ordinary sickness benefit is now 364 days over a period of 450 days, or 15 months. During this time, The Social Insurance Office will, at specified intervals, judge whether a person can return to work. Exceptions to the rule are possible, and the time a person can receive health insurance can be prolonged.

When the days for which sickness benefit is paid are over, or activities that render compensation come to an end, the process for returning to work starts. Those who do not have a job to return to can take part in a labour market programme provided by The Employment Service. The programme lasts for three months and aims at giving extra support to people who have not worked for a long time.

At the beginning of 2010, 17,850 persons lost their sickness benefit due to the new rules. 14,700 (approx. 80 percent) lost everything. 48 percent of these had disabilities. 12,700 persons started The Employment Service's labour market introduction programme. A third of those who were left without benefits at the beginning of 2010, have now, 6 months later, again applied for sickness benefit. Three months must pass, before a new period can start, and this leaves those involved in a precarious situation.

**532.** The media have reported many cases where persons with severe disabilities are uninsured and can no longer cope with daily life. And it is said that many persons with psychiatric disabilities cannot cope with the increased anxiety and have committed suicide. In September 2010, 23,2 percent, or 3,925 persons, were registered with employment offices without activity benefits.

**533.** The health insurance's new rules have also affected persons with chronic diseases, allergies and quite severe visual impairments, because it has become more difficult to keep a part-time job

with compensation from sickness benefits up to full time. The rules affect those who cannot access necessary workplace adjustments or rehabilitation for work. The system needs to be more flexible, for example allowing the individual to decide whether or not he or she can work full time or part time. Because of the rules, some are forced to work 50 percent instead of 60 percent. This lack of flexibility affects an individual's financial situation.

**534. COMMENT**

- The health insurance system must protect persons with disabilities against destitution due to not being able to work because of ill health or disability. The individual's means of supporting him or herself must never be put in jeopardy because there are no jobs or because activities are substandard or non-existent. A person who is afflicted with ill health should not be afflicted with poverty, thus the Swedish health insurance system must be improved.

**Article 28 2.C Financial Support for Added Costs**

**535.** Persons with severe visual impairment or hearing loss are guaranteed disability allowance. Apart from this, there are no limitations due to the type of disability a person has. Individual assessments are made and decisions taken regarding a person's need of support and added costs. Another example is support for the use of a car.

**536. COMMENT**

- The opportunity for persons to receive compensation for added costs is basically good. However, the system needs more flexibility and an updating in order to cover the actual added costs.
- Financial compensation and support in connection with added costs due to disabilities, should not be dependent on whether or not a person has a job. This is often the case when a person uses a car. People must be able to receive compensation for added costs regardless of how much they work.

**Article 28 2. E. Retirement Benefits and Programmes**

**537.** Persons with disabilities are covered by the same retirement rules as persons without disabilities. The retirement system, however, is disadvantageous to many persons with disabilities because a pension is based on an income. Low income, due to for example, unemployment, part-time jobs or early retirement/sickness benefit, follows a person through life, resulting in a low pension.

**538. COMMENT**

- Persons with disabilities, who during their working lives were forced into poverty because of, for example, lack of support to find work or employers' negative attitudes, must enjoy reasonable living conditions after retirement. Supplementary compensation in connection with retirement must be considered.

**539.** The Disability Movement's recommendations, see annex 2

**Article 29 Participation in Political and Public Life**

**Article 29 A. Participation in Political Life**

**Regulatory framework**

**540.** All Swedish citizens, regardless of functional capacity, have the right, protected in the constitution, to vote and take part in the political process.

### **Inadequate accessibility to polling stations**

**541.** According to The Election Act (Vallagen), municipalities must provide accessible polling stations.

Certain exceptions are allowed but only in collaboration with the county administrative board. (Apart from The Election Act there are other laws that stipulate accessibility in public buildings, see Article 9).

**542.** In connection with the election in 2010, the network “Young people for accessibility” investigated accessibility in 77 polling stations. The result was disheartening and shows, for example, that every fourth polling station that was investigated, was not accessible to wheelchair users.

#### **543. COMMENT**

- Negligence to abide by legal regulations in connection with accessibility must be judged lawfully as discrimination.

### **Inadequate accessibility to information in connection with elections**

**544.** Much of the information on which people base their decisions is oral. The political debates are examples of this. The lack of sign-language interpreters, written interpretation and texting for television programmes means that deaf persons and the hard of hearing often miss important oral information that tells about the opinions of parties and representatives. Political information via the television is also unsuitable for persons with electro hypersensitivity. Political debates held in parliament can be heard by persons who are electro hypersensitive via a special phone number. But the television debates are completely ruled out for electro hypersensitive persons.

#### **545. COMMENT**

- Use of necessary information and communication technology to improve access for persons with disabilities to public meetings, must be promoted.
- Access to writing and sign-language interpreters must be easier.
- The authority for radio and TV must use the new “Radio and TV Act” forthwith.(see further Article 21). The technology that makes the media more accessible is already in existence, for example texting, visual interpretation, text reading and so on, and must be used as much as possible.
- Alternative solutions for taking part in political debates and information via television must be introduced.

### **Vote by secret ballot**

**546.** Persons who have problems with reading or writing are not able to use their right to choose a specific candidate secretly. Persons who have, for example, visual impairments, can get their ballot papers with information in Braille or in large print thus allowing an individual to choose which ballot paper he or she wishes to use/which party to vote for. With the present system, however, it is not possible for a person who has problems with reading or writing, to vote for a chosen candidate without asking for help.

#### **547. COMMENT**

- There are several ways in which a person, who has problems with reading and writing, can vote by secret ballot for a specific candidate. The Election Authority must also, in accordance with Article 4, item 3, cooperate with the disability organisation in question, so that satisfactory solutions are reached.

## **Article 29 B. Participation in the Country's Public and Political affairs**

### **Participation in political parties**

**548.** As shown in the disability movement's alternative report on ICCPR, Article 25, participation in political parties is lower among persons with disabilities than in the population as a whole. No party has, as yet, shown any interest in using disability quotas. If they did, it would mean, in theory, that 15 percent of a party's members had some form of disability. This is not the case today. The reasons for this are inaccessibility to the physical environment and to information, and to prevailing attitudes. Other reasons why persons with disabilities are not keen to engage in political matters are inadequate mobility services and escorts and lack of interpreters and assistance (see items 550-551).

#### **549. COMMENT**

- Political parties must be encouraged to involve persons with disabilities, and also to learn how they can make their information and activities accessible to persons with disabilities.

### **Participation in local democracy**

**550.** The Local Government Act (Kommunallagen<sup>149</sup>) states that municipalities and county councils shall work to enable elected representatives with a disability to participate in dealing with matters on equal terms with other elected representatives. In 2006, the authority Handisam was commissioned to investigate whether the provision had led to increased accessibility to political affairs in municipalities and county councils. The result showed that only two thirds of the elected representatives in municipalities and county councils considered that persons with disabilities were treated equally in their work. About half of the elected representatives thought that measures to improve accessibility had been highlighted in plans for activities. A fifth said that they that no documents, or just a few, were available in, for them, suitable formats. Only four of ten municipalities, and eight of ten county councils, had rostrums that were accessible to elected representatives in wheelchairs. Happily, 93 percent of municipalities/county councils reported that their premises for council meetings were equipped with the necessary assistive technology for persons hard of hearing.

#### **551. COMMENT**

- All public players must ensure that the necessary equipment is installed, so that political debates and decision making are accessible to persons with disabilities.
- Public players must take measures to compile routines for the accessibility of their information so that all persons, regardless of disability, can participate.
- Existing technology must be used.
- Use of sign language and writing interpretation must be included in the so-called principle of responsibility and financing in order to become an integral part of work for accessibility.
- Neglect to take measures for accessibility must be judged by law as discrimination.

### **Travelling to and from meetings**

**552.** It is shown in the alternative report on ICCPR, in Article 25, how difficult it is for individual politicians with disabilities, to travel to and from meetings. It applies in particular to those who are dependent on the special transport service. The municipalities and the county council that is responsible for the special transport service, have put a number of measures into place to reduce the cost of the service. Among other things, there are restrictions in the allocation of journeys, and car-pooling is common. This places demands on the travellers to make advance bookings and prioritise their journeys. The result is that travellers are less able to decide themselves when to be collected. Several elected representatives who are dependent on the special transport service say that the rules have made it more difficult to carry out the tasks they have been entrusted with. Party political engagements and municipal posts are often associated with a lot of travelling. When political work entails journeys abroad, it is not often possible for persons who need

interpreters or escorts to take part, as these forms of personal assistance are not granted for travels abroad. For further information concerning personal mobility see Article 20.

### **Freedom of association**

**553.** Persons with disabilities have equal rights with others to start and engage in organisations. Neither are there any limitations in current Swedish legislation concerning freedom of association. On the other hand, inadequate accessibility to premises, activities and information, means that persons with disabilities cannot participate in organisations on equal terms.

**554.** The Disability Movement's recommendations, see annex 2

## **Article 30 Participation in Cultural life, Recreation, Leisure and Sport**

### **Article 30 1. Participation in cultural life**

#### **Regulatory framework**

**555.** In Sweden, persons with disabilities have equal rights with others to participate in and practise culture. The non-discrimination law bans discrimination in the culture sector. However, inadequate accessibility and lack, for example, of escort service, limit a person's actual opportunity of taking part in cultural activities. The regulations concerning accessibility in public premises are described in Article 9. The regulations covering escort service, personal assistance and interpreters are described in Article 19. The Swedish Arts Council (Statens kulturråd) has the collective responsibility, a sector responsibility, of making cultural life accessible to persons with disabilities.

#### **556. COMMENT**

- The efforts made by the Swedish Arts Council are significant and increase accessibility in cultural life. Nevertheless, much remains to be done before persons with disabilities can participate in cultural activities on equal terms with others.

#### **Statistical comparisons and research results**

- **557.** A third of those questioned who were deaf-blind said that they never take part in leisure activities outside the home because their disability makes it difficult for them to do so.<sup>150</sup>
- Persons who are covered by the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), partake to a lesser extent in cultural life and in leisure and sport activities than the population as a whole. Persons subject to the Social Security Act, (Sol) partake even less in these leisure activities. The reasons given for the fact that persons with disabilities more seldom partake in culture and entertainment, take fewer holidays and ,have less access to computers than the population as a whole, are bad economy and inaccessibility. Another reason given, was that users do not have enough influence over the way things are done.<sup>151</sup>
- The more his or her mobility is reduced, the less a person participates in cultural activities. Persons with quite severe mobility disabilities, very seldom go to the theatre or to a concert or to the cinema compared to persons without reduced mobility. It is also less common among persons with reduced mobility to visit a library or a church service, or to read books. Very insignificant differences are shown for the practice of music<sup>152</sup>

## **Article 30 1. A Access to Cultural Material**

**558.** The Talking Book and Braille Library (TPB) and the Easy-to-Read Foundation (CLL) work continuously to develop and provide accessible literature, magazines and news.

### **559. COMMENT**

- Cultural material in accessible formats, is not hard to find, particularly books and other printed material. However, as shown in Article 26, the funds allocated are inadequate and this makes it substantially more difficult to access available cultural material. Books produced in electronic formats require the necessary technical equipment.
- Literature in sign language is hard to find, and production must increase.

## **Article 30 1. B Access to TV, Films, Theatres and Other Cultural activities**

### **Television programmes in accessible formats**

**560.** A compilation of the programme corporations' annual reports shows that all television channels today lack:

- o quality simultaneous texting
- o texting of regional news programmes
- o texting on the web (SVT Play, TV4 Play etc)

The quality of texted programmes has improved, but there is still much to do.

### **Films at the cinema**

**561.** In 2009, 10 out of 30 new Swedish films had one or two copies supplied with text to be shown at cinemas around the country. There is thus only a limited choice of texted Swedish films available. The films are often shown in the daytime, which makes it difficult for persons who work or study, or have some other daytime activity to see the films. The advancement of digital cinemas will help promote texted Swedish films being shown more often and simultaneously at cinemas, but it is taking a long time.

### **The performing arts in accessible formats**

**562.** The Swedish Arts Council's questionnaire among regional institutions of culture, free theatre groups and arrangers of music events found that:

- o Only half of those who answered had operating loop systems or the equivalent.
- o Texted theatre is scarce and found mainly at state-run theatres in Stockholm and Gothenburg and at The National Theatre.
- o Museums often lack written information about their exhibitions. This makes it extremely difficult for persons who have no use for oral presentation, to enjoy the exhibition or the activity. Sometimes there are short written presentations, but this does not give the visitor the same information as does a guided tour.
- o Despite Finish being one of Sweden's minority languages, an investigation carried out by Sweden-Finnish Association of Visually Impaired showed that in 9 of 15 districts, no visual interpretation in Finish was available (for theatre, films and other culture events).

### **563. COMMENT**

- Television programmes, films, theatres and other culture activities in accessible formats (texting, absence of interfering background noise) and interpretation (written interpretation and sign-language interpretation) and operating loop systems are not available to a satisfactory degree.
- Technology to render the media more accessible, for example by texting, through visual interpretation, reading aloud, and more, already exists and must be put to use as far as is possible

- More television programmes need sign-language interpretation. This applies to programmes both for adults and for children. Transmission time for programmes that are sent directly with sign language must also increase.
- Systems for video guides in mobile phones and on displays which people can borrow at museums and exhibitions for guidance in sign language need to be introduced. The technology exists, among other places in Finland.

### **Article 30 1. C Physical Access to Institutions of Culture**

**564.** The Swedish Arts Council's<sup>153</sup> questionnaire found that:

- Half of the institutions said that visitors who are wheelchair users can manage the public parts of the premises on their own, such as the lobby, the toilets and the auditorium. A fourth of these say that the premises are only partly accommodated in this way.
- A third of the institutions say that they have some kind of tactile or contrast markings in the public parts of the premises.
- Half of the institutions have a loop system in operation, or the equivalent, in the public parts of the premises.
- A tenth of institutions say that they have routines for how the staff can answer questions using video phones and text telephony.
- Two thirds said that some of the staff at the institutions had take part in study courses about accessibility and how to approach persons with disabilities.

Four of ten institutions say that the most common reasons for not having implemented accessibility are lack of financial and human resources. A third say that they do not have the knowledge about what needs to be done. One of six institutions says that the management does not prioritise accessibility. Many feel that the goals and tasks set from the management are not explicit enough. There should be guidelines and plans of action that support and legitimise the work and resources that are put to use.

#### **565. COMMENT**

- In Sweden there is legislation that aims at making public places accessible for persons with disabilities. Negligence to take necessary measures that are already laid down in the law, must be judged by law as discrimination
- Explicit guidelines must be introduced, concerning how culture and leisure activities can be rendered accessible to diverse persons with disabilities.
- Many persons with asthma and allergies find it difficult, sometimes impossible, to visit institutions of culture because of other visitors' use of strong perfumes or the smell of tobacco. Information campaigns about this must be carried out.

### **Article 30 2. Utilising Creative, Artistic and Intellectual Potential**

**566.** The Swedish Arts Council notes that, "it is, unfortunately, far too common that artists with disabilities are not given places on study courses, on arenas or on stages. Few courses for performance artists that are accessible to persons with disabilities are organised. Neither are there any such courses in sign language. But there are signs that things are changing. The Stockholm Academy of Dramatic Arts in Stockholm is planning a theatre course for deaf people. Three wheelchair users have applied for places at the course for performance artists in Gothenburg, to name a few."<sup>154</sup>

#### **567. COMMENT**

- Persons with disabilities must be encouraged to utilise their cultural potential and it must be made possible, both at amateur and professional levels. It is important not to forget the "small groups" of blind-deaf and deaf persons with learning difficulties. They must also be able utilise their cultural potential.

### **Article 30 3. Provisions for Intellectual Property Rights**

568. All created works are under Swedish law<sup>155</sup>, protected against copying and illegal use for up to 70 years after the death of the creator. Exceptions may be granted, however, to allow works to be made accessible to persons with disabilities.

### **Article 30 4. Deaf Culture**

569. The deaf culture is a way of life, for which the prerequisite is sign language. Deaf culture is the experience, knowledge, values and norms that are adapted and distributed, and through sign language become common to the deaf group.

#### **570. COMMENT**

In Sweden, the deaf take part in many activities, sports clubs, caravan clubs, bridge clubs, dog clubs and clubs for deaf homosexuals and more:

- Deaf of all ages, regardless of gender, origin, sexual orientation or occupation must have the possibility of learning and using sign language.
- All deaf persons must have access to information about deaf culture, and be encouraged to take part.
- All deaf persons, but also other “groups” of persons with disabilities who share a common culture, must have the opportunity to practice their culture in order to promote a feeling of togetherness, belonging and identity.

### **Article 30 5. Promoting Participation in Sports and Cultural Life**

#### **Sports at school**

571. In the spring of 2010, the Schools Inspectorate carried out unannounced visits to 172 schools in 64 municipalities for the purpose of studying the school subject, sport and health. The Schools Inspectorate found that 2 percent of the pupils had permission to be excused, wholly or partly, from school sports. The Schools Inspectorate notes that this is an unexpectedly high percentage as the possibility of being excused is very limited in the Education Act. The inspection<sup>156</sup> shows that the results were the same for boys and girls. The reasons for being excused are not explained. The disability movement’s experience tells us, however, that many of the pupils who are excused from school sports, have, with all certainty, some form of disability. One of the mainstays of the Swedish school is that all pupils should be able to partake according to their ability and that school, as far as possible, must adapt the teaching to suit pupils’ diverse capabilities. Before a pupil is excused from taking part in a subject, the school must try and find other ways of accommodating the teaching. Sport and health has a broad subject matter in order to accommodate pupils’ diverse prerequisites and needs. The inspection shows, however, that lessons do not always follow the provisions in the plans.

#### **572. COMMENT**

- If teaching is carried out in such a one-sided way as the inspection found, it will be difficult to find opportunities of accommodating sports lessons.
- The main principle must be that pupils with disabilities should not be forced to opt out of sports lessons just because they have a disability.
- Sports teachers must be encouraged to carry out their lessons in a way that is accessible to many kinds of pupil. If pupils cannot take part because of their disability, there must be alternative arrangements.
- Good examples of activities that work for pupils with different types of disabilities must be continually updated and disseminated so that sports teachers have access to ideas about how lessons can be given.

### **Assistive devices for sport and leisure activities.**

**573.** It is difficult to acquire assistive devices and interpretation for leisure activities. County councils do not prioritise everyday interpretation for leisure very highly, which can be seen in county councils' fixed list of priorities, and has been commented on in the Board of Health and Welfare's report (2008): "The term everyday interpretation. Concerning county councils' responsibilities towards the deaf, deaf-blind and persons hard of hearing".

### **Article 30 5. D Leisure and Playtime for Children**

**574.** The Consumer Agency's market control<sup>157</sup> of playgrounds from 2008, found that there are inadequacies concerning accessibility and usefulness.

- Many playgrounds have surfaces often sand or grass that make it difficult to move about in a wheelchair or get to the play apparatus.
- Many playgrounds lack clearly defined guidance routes and orientation points.
- Playground apparatus are often designed for children who have full mobility.

#### **575. COMMENT**

- How to achieve accessibility in playgrounds must be studied.

**576.** The Disability Movement's recommendations, see annex 2

### **Article 31 Statistics and data collection**

**577.** Sweden collects a considerable amount of statistics and information. A comparison of the information and statistical data available when the two previous reports on economic, social and cultural rights and civil and political rights were presented, shows that statistics today are more often broken down, especially by gender and age. (This does not apply however to statistics concerning children with disabilities). Events are progressing in the right direction but, despite this, we would like once more to point out the significance of always breaking down figures on several grounds, especially disability, age and gender; but also ethnicity, religion and sexual identity. This is for the identification of cases of multi-discrimination. In order to be able to measure development, it is essential that repeated/comparative studies related to all areas of rights be carried out regularly. This includes amendments to the regulatory framework, administration, implementation of the regulations and the outcome of measures taken, ie how living conditions for persons with disabilities are affected. The considerable decentralisation chosen by Sweden has made it more difficult to monitor changes within the municipalities.

Statistics Sweden has been authorised by the government to analyse statistics concerning children and give proposals as to how the current collection of statistics and surveys can be developed to highlight the circumstances of children and young people with disabilities. The disability movement welcomes this task but would like to emphasise how important it is that the statistical model chosen does not involve any form of classification or categorisation of children with disabilities.

The disability movement has no points of view on the regulatory framework for secrecy and the prohibition of unlawful processing of personal data, the use of personal data in unstructured material etc.

#### **578. COMMENT**

- At the time of assembling this report, facts and statistical grounds/comparisons for several areas were missing. A list of these areas can be found in the Swedish version of the report.

## **Article 32 International Cooperation**

**579.** Swedish International Development Cooperation Agency, SIDA, has presented a plan, authorised by the government, to ensure that human rights for persons with disabilities are taken into account in SIDA's internal work and work carried out within the framework of the agency's bilateral development cooperation. A detailed plan for work done from 2009 to 2012 has taken form and is currently in use.

**580.** Every year, in February, the foreign minister presents the government's declaration of foreign policy in parliament. This "foreign declaration" designates which direction the government's foreign policies will take for the coming year. The government has never mentioned the convention in its foreign declaration during the years since Sweden ratified the convention.

**581.** In the government's report on Sweden's policies for global development and cross-border matters that have international repercussions, the convention is mentioned only in passing and not in a manner fitting the significance the convention should have in this work.

**582.** The Swedish disability organisations' international cooperation (SHIA) through its 30 member organisations, pursues development cooperation that reinforces capacity in partnership with their respective sister organisations in the developing countries.

### **583. COMMENT**

- We welcome the government's initiative in presenting a plan that includes persons with disabilities in all work done to develop cooperation. Naturally we also welcome the support SIDA gives to DRPI and IDA. However, we believe that considerably more can, and therefore must, be done. The fact that Sweden has ratified the convention must make a distinct mark on Sweden's foreign policy and policies for global development. The knowledge gained by individuals working with SHIA's activities must be handled much more seriously.

584. The Disability Movement's recommendations, see annex 2

## **Article 33 National implementation and monitoring**

The inquiry is in progress. Currently the final report from the Delegation of human rights in Sweden is dealt with by "A New structure for protection of human rights" SOU 2010:70

## **Annex 1: Organisations that support the report**

### **The Swedish Disability Federation**

Bloodcancer Association  
HIV-Sweden  
Mouth & Throat Cancer Association  
National Organization of Cancer of the Prostate  
Primary Immunodeficiency Organization  
Swedish Aphasia Association  
Swedish Association for Kidney Patients  
Swedish Association for the ElectroSensitive  
Swedish Association of Brain Injured and Families  
Swedish Association of People with Mobility Impairments  
Swedish Association of People with Stomach and Bowel Diseases  
Swedish Association of Dental Mercury Patients  
Swedish Association of Rare Disorders  
Swedish Asthma and Allergy Association  
Swedish Breast Cancer Association  
Swedish Coeliac Society  
Swedish Cystic Fibrosis Association  
Swedish Diabetes Association  
Swedish Epilepsy Association  
Swedish Fibromyalgia Association  
Swedish Heart – Children´s Association  
Swedish Hemophilia Society  
Swedish National Association Attention  
Swedish National Association for Deaf, Hearing impaired and Language impaired Children  
Swedish National Association for Social and Mental Health  
Swedish National Association of the Deaf  
Swedish National Society for Persons with Intellectual Disability  
Swedish OCD-foundation Ananke  
Swedish Ostomy Organisation  
Swedish Parkinson´s Disease Association  
Swedish Psoriasis Association  
Swedish Rheumatism Association  
Swedish Schizophrenia Fellowship  
Swedish Stroke Association  
Swedish Stuttering Association  
The National Society of Autism and Asperger  
The Swedish National Dyslexia Association  
The Swedish Association for Survivors of Accident and Injury (RTP)  
The Swedish National Dyslexia Association - FMLS

### **Equally Unique, the Swedish Federation Human Rights for Persons with Disabilities**

The Association of the Swedish Deafblind  
The National Association for Disabled Children and Youths  
The Swedish Association of Hard of Hearing People  
The Swedish Association of Persons with Neurological Disabilities  
The Swedish Association of the Visually Impaired

**Other organisations of people with disabilities**

The Swedish National Association of Late Deafened Adults  
Forum Women and Disabilities

**Organisations for young people with disabilities**

Swedish Deaf Youth Association  
The Swedish Association of Visually Impaired Youth

**Other organisations**

CEDAW Network Sweden  
Lions Clubs International MD 101  
Soroptimists Sweden  
Swedish Committée of Rehabilitation International  
The Swedish Women´s Lobby  
United Nations Association of Sweden  
YWCA-YMCA of Sweden

## **Annex 2: The Disability Movement's Recommendations to the Swedish State**

### **Article 1 Purpose**

(no recommendations)

### **Article 2 Definitions**

#### **18. The Disability Movement's Recommendations to the Swedish State:**

- Implement information campaigns for increased understanding by the judiciary and decision makers about what the different concepts mean.
- Commission a survey and implement necessary changes of the regulatory framework, so that the definitions in article 2 are secured and applied.
- Ensure that efforts to increase awareness about persons who use sign language and about the Swedish sign language are implemented.

### **Article 3 General principles**

#### **20. The Disability Movement's Recommendations to the Swedish State:**

- Initiate substantial information campaigns about human rights in connection with persons with disabilities. The campaign should stress the importance of the general principles listed in article 3 as guidelines for all decisions concerning the rights of the convention, likewise all decisions at national, regional and local levels.

### **Article 4 General obligations**

#### **33. The Disability Movement's Recommendations to the Swedish State:**

- Develop methods to ensure that the existing regulatory framework at all levels of society and within all sectors is complied with.
- Give an account forthwith to parliament of how the recommendations in this report from the disability movement shall be handled.
- Make sure that at all levels the disability movement is invited to collaborate and that sufficient resources are provided in order to implement the convention in the best way possible.

### **Article 5 Equality and non-discrimination**

#### **52. The Disability Movement's Recommendations to the Swedish State:**

- Take measures to ensure that the lack of equality in the eye of the law described in items 34-41 is resolved so that Sweden can be said to live up to Article 5 1.
- Guarantee that prohibition of discrimination due to disability is included in relation to all rights in the Convention.
- Introduce rules to regulate the use of non-discrimination clauses for all public service contracts.

- Guarantee that individuals in Sweden receive equal support and access to effective legal aid for the protection of civil and political rights, economic, social and cultural rights.
- Take measures to ensure that the Discrimination Ombudsman can pursue cases in a court of law that are based only on The European Convention on Human Rights and Fundamental Freedoms.

## **Article 6 Women with Disabilities**

### **65. The Disability Movement's Recommendations to the Swedish State:**

- Take measures to ensure that the perspective of gender and disability permeate surveys, plans, implementation, evaluation and revision at all activities in society and at all levels and within research.
- Launch an inquiry that takes a thorough look at, and documents, the degree to which women and girls with disabilities are discriminated against compared to men and boys with disabilities
- Take measures to ensure that all statistics show the gender division
- Launch an inquiry to find out the causes of, and suggest solutions to combat the current differences between men and women with regard to disability connected to the environment.

## **Article 7 Children with disabilities**

### **96. The Disability Movement's Recommendations to the Swedish State:**

- Create a regulatory framework that safeguards coordination and content of activities where the state, municipalities and county councils are jointly responsible.
- Ensure that sanctions are introduced for cases where decisions in keeping with the act concerning support and service for certain disabilities are not implemented.
- Create new national guidelines that include the minimum level of support and education that should be offered to all parents of children with disabilities.
- Initiate a comprehensive survey of how pre school activities provide for children with disabilities, and arrange continual supervision in order to ensure that satisfactory childcare is in place for all children with disabilities.
- Ensure that children with serious diseases or disabilities are not deported to countries where they cannot access medicine, assistive devices, education, basic habilitation and communications such as sign language.
- Ensure that this convention is coordinated with the convention of the Rights of a Child to secure that the situation for children with disabilities is strengthened.

## **Article 8 Awareness-raising for persons with disabilities**

### **114. The Disability Movement's Recommendations to the Swedish State:**

- Create a strategy that increases public knowledge about different (visible and invisible) physical, mental, intellectual and sensory disabilities and their consequences and understanding that shortcomings in society exclude persons with disabilities. Funds and resources to implement the strategies' various components must be allocated.

- Institute vigorous measures with the aim of increasing awareness about the diversity of persons with disabilities in steering documents at different types of schools and the production of textbooks.
- Review the current public service agreement with Swedish Television in order to guarantee a portrayal of persons with disabilities that does not reinforce stereotypes and attitudes that make it more difficult for persons with disabilities to integrate in society. Models of organised work for diversity in public service media can be found on the international arena, among these the media platform on which the BBC bases its work.
- The state and the media corporations shall in a dialogue with the disability movement take responsibility for the inclusion of persons with disabilities in the media. (items 145-149)
- Oversee that regular and systematic independent reviews of the medias' portrayal of persons with disabilities are undertaken
- Encourage strategic recruitment within the media and the public sector to showcase examples.
- Institute forthwith a review of universities, institutions of higher education and vocational training that are in need of "disability knowledge"
- Develop comprehensive courses for identified/different vocational groups and encourage supplementary training for the employed.

## **Article 9 Accessibility**

### **178. The Disability Movement's recommendations to the Swedish State:**

- Safeguard forthwith that the regulatory framework covering accessibility is complied with.
- Urge the supervisory authorities/municipalities to apply the penalties currently incorporated in The Planning and Building Act, if obvious inadequacies of accessibility are not dealt with.
- Ensure that failure to take measures for accessibility is judged as discrimination.
- Implement a comprehensive review of the regulatory framework concerning accessibility in built-up environments. Measures must be taken to rectify the inadequacies highlighted by the Swedish disability movement so that Sweden has a regulatory framework that lives up to the demands of the convention.
- Supplement the regulatory framework concerning the public sector's responsibility to present its information and communications in a manner accessible to persons with disabilities, as seen in item x.
- Promote monitoring systems in order to follow up both private and public parties' work to make their information and communications accessible to persons with disabilities.
- Introduce a coordinated transportation system for assistants to accompany persons with disabilities, so that it is possible to travel freely and change mode of transportation and travel company without problems.
- Safeguard that education dealing with built-up environments contains information about accessibility and universal design, establish introductory courses about accessibility and usability for persons with different disabilities and special courses within different areas of accessibility, and encourage key persons or persons who are interested, to get some training.

## **Article 10 Right to life**

### **188. The Disability Movement's Recommendations to the Swedish State:**

- Undertake a survey of the reasons for deaths among girls, boys, women and men with disabilities.
- Secure that the county councils take necessary measures to reduce mortality among patients with mental ill health.
- With an aim to reducing mortality within health and medical care, the legal regulatory framework covering patient security must be revised. This includes
  - ensuring that reports are lodged more frequently from both carers and patients so that inadequacies in healthcare are always highlighted,
  - developing a system that deals with these matters so that all aspects of health and medical care are systematically monitored and quality assured,
  - a national feedback system must be in place for the implementation of nationwide patient security
- Ensure that violence and abuse against girls, boys women and men with disabilities can be identified and that necessary support is at hand. A survey is needed of lethal violence and suicide among persons with disabilities who are exposed to violence. The survey's findings must be used to facilitate the identification of all forms of lethal violence and to stop them.
- Secure that persons with serious diseases or disabilities have access to life prolonging drugs while waiting for residence permits and that they cannot be deported or expelled if deportation could lead to death.

## **Article 11 Situations of risk and humanitarian emergencies**

### **203. The Disability Movement's Recommendations to the Swedish State:**

- Ensure that there are sufficient accessible alerting systems/communication channels so that persons regardless of disability can alert and be aware of an alarm in an emergency situation.
- Ensure that municipalities include persons with disabilities in their plans for dealing with extraordinary situations.
- Create indicators that gauge the quality of municipalities' risk and vulnerability analyses and highlight persons with disabilities in their crisis management plans.
- Create a cognitive, visual support for evacuation.
- Carry out a survey of the accessibility of evacuation routes at all public players and

## **Article 12 Equal Recognition before the Law**

### **209. The Disability Movement's Recommendations to the Swedish State:**

- Ensure that trustees or other less intrusive assistance replace administrators when an individual is no longer in need of an administrator. A point of time for reassessment must be introduced.

- Create national guidelines concerning adequate knowledge for trustees and administrators and for how they are appointed. The task must be defined and an individual's opportunity to influence the work and who carries it out must be reinforced.

## **Article 13 Access to Justice**

### **232. The Disability Movement's Recommendations to the Swedish State:**

- Commission the relevant authorities of the judicial system to account for how current regulations concerning accessibility to physical environments, information and communications, including access to interpreters, are carried out and what measures have been taken to increase accessibility.
- Review, clarify and reinforce current legislation so that individuals, regardless of their role in judicial proceedings, are guaranteed the opportunity to receive written and oral information in alternative formats or through an interpreter supplied by the courts or the administrative authority.
- Commission the National Police Board to account for how girls, boys, women and men with disabilities are treated during the part of legal proceedings that the police are responsible for, concerning how, where and by whom persons with disabilities are interviewed.
- Ensure that the entire judicial system interprets the law in a manner that conforms to the rights of the convention.
- Secure that legal aid also covers social security cases and cases involving social legislation.

## **Article 14 Liberty and Security of Person**

### **254. The Disability Movement's Recommendations to the Swedish State:**

- Implement the proposal of the committee of mental responsibility on closed accommodation for certain offenders.
- Ensure that the courses at the National Police Academy include the subject "disabilities" and handle general treatment, accessibility and interrogation methods.
- Implement a survey of accessibility for persons with diverse disabilities within the Prison Services' activities and youth detention centres.

## **Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment**

### **263. The Disability Movement's Recommendations to the Swedish State:**

Commission the National Board of Health and Welfare to define the concepts of violence, lethal violence and legitimate restraint techniques.

- Create guidelines for how personnel may treat people who are emotional and confused respectfully and avoid lethal violence.

- Launch an inquiry into how the National Board of Health and Welfare's supervision can include both the formalities of activities and also attitudes and treatment together with the content and design of activities.
- Implement a review of the principles of informed consent.

## **Article 16 Freedom from Exploitation, Violence and Abuse**

### **291. The Disability Movement's Recommendations to the Swedish State:**

- Ensure that violence and abuse against girls, boys, women and men with disabilities can be identified and that necessary support is at hand.
- The issue must be addressed in national training courses for groups of personnel working with health and medical care, schools and within the police force and judiciary.
- Ensure that the National Board of Health and Welfare's supervision of health and medical care and other special services also includes analysis of how abuse against people with disabilities can be reported and dealt with.
- Ensure that the social services and health and medical care services comprise strategies and methods for the support of girls, boys, women and men with disabilities who have been exposed to different types of abuse.
- Ensure that women's and men's support centres' facilities are made accessible to women and men with disabilities, especially the physical environment, information and communications.
- Review current guidelines for personnel in special services care with an aim to reinforce competence and the ability to intervene when violations occur at various types of special housing,

## **Article 17 Protecting the integrity of the person**

### **296. The Disability Movement's Recommendations to the Swedish State:**

- Take measures to ensure that the new instruments evolving for assessing needs are created in collaboration with representatives from organisations for disabilities.
- Supplement the Social Services Act with "rules" that highlight activities that are best administered by a limited number of carers.

## **Article 18 The Right to Liberty of Movement and Nationality**

### **304. The Disability Movement's Recommendations to the Swedish State:**

- Ensure that persons with disabilities have real opportunities to profit from their right to freedom of movement including the right to choose where they live. See recommendations in articles 9, 19 and 20.
- Commission the Migration Board to account for how asylum seekers with disabilities are treated within all parts of immigration proceedings.
- Review the Aliens Act and make necessary amendments in order to safeguard that disabilities and access to adequate medical care in home countries are taken into

consideration. Persons with disabilities must have equal chances to remain in the country compared to anyone else in a similar situation.

## **Article 19 Living independently and being included in the community**

### **325. The Disability Movement's Recommendations to the Swedish State:**

- Review The Law Concerning Planning Permission and Building Regulations (Bygglagen), Ordinance for Planning and Building (Plan-och byggförordningen) and the regulations for how buildings are designed, so that all housing, new and renovated, is accessible and usable for people with impaired capacity.
- Review the law concerning housing adaptation grants (and other supplementary regulations) so that people with disabilities have equal opportunities with others to choose whether to change residence or stay where they are. Measures taken due to the need of personal assistance must be included in law. Landlords' possibility of stopping adaptation must be removed.
- Review The Social Security Act (Socialtjänstlagen) so that it clearly states that people with disabilities must have access to the service required for an independent life, the cost of which should be reasonable.
- Clarify The Act Concerning Certain Support and Service for Persons with Functional Impairments (Lagen om särskild stöd och service till vissa funktionshindrade), so that there can be no doubt that people with severe visual impairments belong to group three.

## **Article 20 Personal mobility**

### **346. The Disability Movement's Recommendations to the Swedish State:**

- Intensify the work done to render transport, buildings and information connected with travelling accessible for persons with disabilities.
- Clarify and supplement the regulatory framework with special transport services and national special transport services to facilitate/make possible personal mobility in the manner intended by the convention.
- Implement a comprehensive survey of the car allowance. The starting points for such a survey must be discussed together with the disability movement.
- Develop systems to allow individuals to access temporary activities such as personal assistance in connection with travel abroad.

## **Article 21 Freedom of Expression and Opinion, and Access to Information**

### **364. The Disability Movement's Recommendations to the Swedish State:**

- Supplement the regulatory framework concerning the public sector's responsibility for presenting accessible information and communication to people with disabilities in the manner defined in the comment in item 349.

- Develop follow-up systems for the monitoring of private and public players' endeavours to make their information and communication accessible to people with disabilities.
- Negligence to take measures to ensure accessibility in accordance with the existing regulatory framework must be judged by law as discrimination.

## **Article 22 Respect for Privacy**

### **372. The Disability Movement's Recommendations to the Swedish State:**

- Ensure that the regulatory framework is amended so that harmful, arbitrary and unnecessary interference in children's privacy is prohibited.
- Look into and ensure that there is informed consent to restrict an individual's right to use a mobile phone etc or to monitor a patient's letters in accordance with the law on compulsory psychiatric care. Also ensure very thorough supervision of the law's enforcement.
- Monitor how the regulatory framework covering secrecy is applied.
- Ensure that an individual's data are not revealed unless he or she has actively given consent.

## **Article 23 Respect for Home and the Family**

### **401. The Disability Movement's Recommendations to the Swedish State:**

- Initiate a survey of the supply, information activities and quality of study material, training courses and counselling at pregnancies, parenthood, sex and cohabitation related to persons with diverse disabilities.
- Initiate a survey of the accessibility and quality of activities provided so that individuals can cope with home and family. Indicators to monitor development must also be introduced.
- Ensure that the National Board of Health and Welfare's handbook on adoption is reworked so that it includes a more correct description of parenthood and the supportive activities that an individual parent with a disability has a right to.
- Ensure that parents of children who are deaf, deaf-blind or hard of hearing receive adequate instruction in Swedish sign language.

## **Article 24 Education**

### **442. The Disability Movement's Recommendations to the Swedish State:**

- Ensure that teachers' training is supplemented with "disability knowledge".
- Ensure that the Education Act is reviewed forthwith so that pupils receive support for education according to their needs and not just until the end of primary school.
- Ensure that the right to learn practical and social skills, for example Braille and Swedish sign language, to facilitate full and equal participation in education, is recognised forthwith and guaranteed in the Education Act.
- Safeguard that individuals hard of hearing, or who are deaf or deaf-blind, have access to interpreting they understand, regardless of type of school and study programme. There must be a substantial increase in accessible tuition in Swedish sign language in all types of schools.

- Ensure that the wording of the Education Act does not permit schools to refuse entrance to pupils with disabilities.
- Take efficient measures to accelerate work being done to make schools and tuition accessible to pupils with disabilities.
- Ensure that the study programmes of different schools are harmonised so that pupils, regardless of disability, are offered equal education.
- Carry out a new school organization as proposed by the organisations of deaf, hard of hearing and deaf blind, which includes schools with a language profile (Swedish sign language and Swedish), regional resource centers and national coordination.
- Ensure that statistics produced within the education sector are gender-divided.

## **Article 25 Health**

### **458. The Disability Movement's recommendations to the Swedish State:**

- Guarantee that all persons, regardless of disability, gender, age or where in the country they live, have access to equal healthcare, medical treatment and medicines.
- Introduce guidelines for the prescription of drugs for persons with neuropsychiatric disabilities.
- Ensure that there is a more noticeable inclusion of persons with disabilities within the public health sector. Processes and factors that are a hindrance to ability must be highlighted.
- Guarantee that surveys, concerning public health, put special focus on the health of persons with disabilities.
- Give The National Institute of Public Health,(Folkhälsoinstitutet) the task, in collaboration with the Swedish Disability Movement, of developing indicators to measure participation and influence.
- Ensure that persons cannot be denied the right to take out insurance policies due to disabilities.

## **Article 26 Habilitation and Rehabilitation**

### **471. The Disability Movement's Recommendations to the Swedish State:**

- Guarantee that all people receive necessary habilitation and rehabilitation regardless of where in the country they live and irrespective of disability, age and gender.
- Ensure that national regulatory frameworks for habilitation, rehabilitation and the distribution of assistive devices and technology are produced.
- Ensure that all fees for healthcare (including fees for assistive devices) are included in the high fee protection system, as stipulated in the Health and Medical Service Act (HSL).
- Guarantee that specialists in healthcare have sufficient knowledge in their field and ensure that access to education is improved.

## **Article 27 Work and Employment**

### **519. The Disability Movement's Recommendations to the Swedish State:**

- Guarantee that failure to take measures for accessibility is judged lawfully as discrimination.
- Complete regulations so that support is provided for all aspects of work.

- Find a more suitable way of sharing responsibility and working together for assistive devices and personal support for all areas of life.
- Invent a telephone number for comprehensive information about labour market activities.
- Implement information campaigns, the aim of which are to raise levels of knowledge about the diversity among persons with disabilities and the supportive activities society can offer. These campaigns must be undertaken in close cooperation with the disability movement and labour market organisations.
- Take appropriate measures to ensure that more persons with disabilities find work with public employers.
- Ensure that even people that are within the scope ratione personae 3 of Act concerning Support and Service for Persons with Functional Impairments are entitled to daily activities.

## **Article 28 Adequate Standard of Living and Social Protection**

### **539. The Disability Movement's Recommendations to the Swedish State:**

- Initiate an inquiry into the whole system of economic and social security, and suggest solutions as to how persons with disabilities can escape the structural poverty they find themselves in. The starting points for such an investigation must be defined in collaboration with the disability movement.
- Change the rules of the health insurance system so that persons with chronic diseases can keep their jobs and work part time (however much they can manage) and keep their financial compensation up to full time.
- Do away with the 65 year age limits in the social security system. Need, not age, must determine whether a supportive activity is granted.

## **Article 29 Participation in Political and Public Life**

### **554. The Disability Movement's Recommendations to the Swedish State:**

- Supplement the regulatory framework concerning the responsibilities of the public sector to make information and communication accessible to persons with disabilities.
- Guarantee that persons who have problems with reading and writing are able to choose a specific candidate in the secret ballot.
- Ensure that neglect to take measures for accessibility is judged by law as discrimination.

## **Article 30 Participation in Cultural life, Recreation, Leisure and Sport**

### **576. The Disability Movement's Recommendations to the Swedish State:**

- Increase accessibility of television programmes, films, theatre and other cultural activities in suitable formats (texting, absence of interfering background noise) and interpretation (written interpretation and sign language).
- Put in place more explicit guidelines for how culture institutions can be made accessible for a diversity of persons with disabilities.
- Ensure that neglect to take measures for accessibility is judged by law as discrimination.

- Ensure that the training for sports teachers is supplemented with general knowledge about teaching heterogeneous groups where pupils may have some form of disability.

## **Article 31 Statistics and data collection** (no recommendations)

## **Article 32 International Cooperation**

### **584. The Disability Movement's recommendations to the Swedish State:**

- Authorise SIDA to report back on how work to implement the plan to include persons with disabilities is progressing.
- Ensure that SIDA's fundraising shall combine precise requirements that persons with disabilities shall be included in these activities and the activities that the fundraising is addressed to.
- Commission SIDA and the Ministry of Foreign Affairs to account for, in all reports, how circumstances for persons with disabilities have been influenced by development assistance.
- Ensure that the knowledge and experience gained by persons with disabilities through the activities of SHIA are taken into account in other activities for development cooperation.

## **Article 33 National implementation and monitoring**

(no recommendations)

### **Annex 3: Laws**

Act Concerning Support and Service for Persons with Certain Functional Impairments, (1993:387)  
(*Lag om stöd och service för vissa funktionshindrade, LSS*)

Act on Genetic Integrity, (2006:351) (*Lag om genetisk integritet m m*)

Act on Housing Adaptation Grants, (1992: 1574) (*Lagen om bostadsanpassningsbidrag*)

Act on Municipal and County Council Measures Prior to and during Extraordinary Events in Peacetime and during Periods of Heightened Alert, (2006:544)  
(*Lag om kommuners och landstings åtgärder inför och vid extraordinära händelser i fredstid och höjd beredskap*)

Act on Technical Requirements for Construction Works, (1994:847)  
(*Lag om tekniska egenskapskrav på byggnadsverk*)

Act on the Effect of Agreements Entered into under the Effect of Mental Disturbance, (1924:323)  
(*Lag om verkan av avtal som slutits under allvarlig psykisk störning*)

Administrative Court Procedure Act, (1971:291) (*Förvaltningsprocesslag, FPL*)

Administrative Procedure Act, (1986:223) (*Förvaltningslagen, FL*)

Aliens Act, (2005:716) (*Utlänningslag*)

Assistance Benefit Act (1993:389) (*Lag om assistansersättning, LASS*)

Assistance Benefit Ordinance (1993:1091) (*Förordning om assistansersättning*)

Aviation Law, (1957:297) (*Luftfartslag*)

Childrens and Parents Code, (1983:47) (*Föräldrabalk*)

Diseases Act, (2004:168) (*Smittskyddslagen*)

Education Act, (2010:800) (*Skollagen*)

Election Act, (2005:837) (*Vallagen*)

Electronic Communications Act, (2003:389) (*Lag om elektronisk kommunikation, LEK*)

Environmental Code, (1998:808) (*Miljöbalk*)

Health and Medical Service Act, (1982:763) (*Hälso- och sjukvårdslag, HSL*)

Language Act, (2009:600) (*Språklag*)

Law concerning compulsory psychiatric care (1991:1129) (*Lag om rättspsykiatrisk vård, LRV*)

Law on Psychiatric Compulsory Care, (1991:1128) (*Lag om psykiatrisk tvångsvård, LPT*)

Law on Safety in Metro and Tramway, (1990:1157) (*Lag om säkerhet vid tunnelbana och spårväg*)

Maritime Safety Act, (1988:49) (*Fartygssäkerhetslag*)

Parental Leave Act, (1995:584) (*Föräldraledighetslag*)

Penal Code, (1962:700) (*Brottsbalk, BrB*)

Planning and Building Act, (2010:900) (*Plan- och Bygglagen*)

Planning and Building Ordinance (1987:383) (*Plan- och byggförordningen*)

Professional Transport Act, (1998:490) (*Yrkestrafiklag*)

Protection against Accidents Act, (2003:778) (*Lag om skydd mot olyckor, LSO*)

Protection against Accidents Act, (2003:789) (*Förordning till lagen om skydd mot olyckor*)

Public Access to Information and Secrecy Act (2009:400) (*Offentlighets- och sekretesslag*)

Social Security Act, (2001:453) (*Socialtjänstlag, SoL*)

Special Transport Act, (1979:558) (*Lag om handikappanpassad kollektivtrafik*)

Special Transport Act, (1980:398) (*Förordning om handikappanpassad kollektivtrafik*)

Special Transport Act, (1997:735) (*Lag om riksfärdtjänst*)

Special Transport Act's (1997:736) (*Lag om färdtjänst*)

Swedish Code of Judicial Procedure, (1942:740) (*Rättegångsbalk, RB*)

Swedish Constitution, (1974:152) (*Regeringsformen*)

Swedish National Board of Housing, Building and Planning, (2003:19) (*Boverkets Föreskrifter, BFS*)

The Discrimination Act (2008:567) (*Diskrimineringslagen*)

The European Convention on Human Rights and Freedoms and the Law on Prohibition of Discrimination, (1994:1219) (*Lag om europeiska konventionen angående skydd för de mänskliga rättigheterna och grundläggande friheterna, Europakonventionen*)

The ordinance concerning government authorities' responsibilities for persons with disabilities", (2001:526) (*Förordningen om de statliga myndigheternas ansvar för genomförandet av handikappolitiken*)

The public sector's responsibilities during war or the threat of war are found in a law laying down duties for municipalities, administrative authorities and courts during war or the threat of war, [\(1988:97\)](#) (*Lag om förfarandet hos kommunerna, förvaltningsmyndigheterna och domstolarna under krig eller krigsfara med mera*)

Tobacco Act, (1993:581) (*Tobakslagen*)

Work Environment Act, (1977:1160) (*Arbetsmiljölagen*)

Work Environment Authority on workplace design, (2009:2) (*Förordningen Arbetsplatsens utformning, AFS*)

## Annex 4: List of abbreviations

ADHD	Attention deficit/hyperactivity disorder.
BFS	Building Regulation (Boverkets föreskrifter)
BO	The ombudsman for children Barnombudsmannen
BRÅ	The National Council for Crime Prevention (BRÅ)
BUP	Psychiatric Mental Health Care for Children and Adolescents (Barn- och ungdomspsykiatri)
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
DO	Discrimination Ombudsman, DO, Diskrimineringsombudsmannen
DRPI	The National Council for Crime Prevention ( <i>Brå</i> )
ESC	International Covenant of Economic, Social and Cultural Rights
ECT	Electroconvulsive therapy
EG	European Communities, Europeiska Gemenskapen
EU	European Union
FAS	Swedish Council for Working Life and Social Research (Forskningsrådet för Arbetsliv och Socialvetenskap)
Handisam	Swedish Agency for Disability Policy Coordination (Myndigheten för handikappolitisk samordning)
Handu	Swedish Research Institute for Disability Policy, Handu (Utredningsinstitutet Handu)
HIV	Human Immunodeficiency Virus
HSL	The Health and Medical Service Act (HSL) (Hälso- och sjukvårdslagen)
HVB	Supported living service (Hem för vård eller boende)
ICAO	International Civil Aviation Organization
ICT	Information and Communication Technology, ICT
IDA	International Disability Alliance
LASS	Lagen om assistansersättning – se ”grönt” nedan
LO	the Swedish Trade Union Confederation (LO) (Landsorganisationen i Sverige)
LASS	The Assistance Benefit Act
LSS	The Act Concerning Support and Service for Persons with Certain Functional Impairments (Lagen om stöd och service för vissa funktionshindrade)
LVU	The law Care of Young Persons (Lagen om särskilda bestämmelser om vård av unga)
PIVA	Psychiatric intensive care (Psykiatrisk Intensivvårdsavdelning)
RBU	The National Association for Disabled Children and Youths Riksförbundet för Rörelsehindrade Barn och Ungdomar

RGH	Riksgymnasium för hörselskadade
SCB	Statistics Sweden's (SCB) labour force survey (Statistiska Centralbyrån)
SFS	Swedish Code of Statutes (Svensk Författningssamling)
Shia	SHIA, an umbrella organisation for the disability movement that works with international growth Svenska handikapporganisationers internationella utvecklingssamarbete
Sida	Swedish International Development Cooperation Agency (Styrelsen för internationellt utvecklingssamarbete)
SKL	Sweden's Municipalities and County Councils, SKL, (Sveriges Kommuner och Landsting)
SoL	The Social Services Act (Socialtjänstlagen)
SOU	Official Report of the Swedish Government (Statens offentliga utredningar)
SOSFS	The National Board of Health and Welfare's general advice
SRF	Swedish Association of the Visually Impaired Synskadades Riksförbund
Standardreglerna	Standard Rules on the Equalization of Opportunities for Persons with Disabilities
SvD	The daily broadsheet newspaper Svenska Dagbladet
TSD TSD PRM	Technical standard (Teknisk standard) TSD PRM (Transportation Systems Design for Persons with Reduced Mobility) (Tekniska specifikationer för driftskompatibilitet för funktionshindrade)
TUFF	Sign-language training for certain parents (Teckenspråksutbildning för föräldrar)
VGU	The Transport Administration is currently looking into how roads are designed (Trafikverkets "Vägars och gators utformning")
UD	Ministry for Foreign Affairs
UN	United Nations
UPR	Universal Periodic Review

## Annex 5 Footnotes

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<sup>1</sup> Law 1994:1219 – The European convention concerning protection of human rights and fundamental freedoms

<sup>2</sup> National Survey of Public Health - Health on Equal Terms-Swedish National Agency of Public Health

<sup>3</sup> Assistive Technology in Sweden, Swedish Institute of Assistive Technology, 2010

<sup>4</sup> Government bill 2008/09:28, page 8, Mänskliga rättigheter för personer med funktionsnedsättning

<sup>5</sup> Handisam, Öppna jämförelser av tillgängligheten i staten, myndighetsenkät 2010

<sup>6</sup> Official Report of the Swedish Government, SOU 2011:18 Den framtida gymnasiesärskolan – en likvärdig utbildning för ungdomar med utvecklingsstörning

<sup>7</sup> Follow-up of national action plan for disability policy and grounds for future strategy, page 15. Referat från Regeringens skrivelse 2009/10:166

<sup>8</sup> The Education Act (SFS 2010:800) takes effect July 1, 2011.

<sup>9</sup> Law 1994:1219, The European Convention concerning protection of human rights and fundamental freedoms

<sup>10</sup> National Board of Health and Welfare, Jämställd Socialtjänst? Könsperspektiv på socialtjänsten, 2004

<sup>11</sup> SKL 2009 Development is in progress, a survey of the work to combat violence against women in local authorities and regions. (SKL 2009 Utveckling pågår, en kartläggning av kvinnofridsarbetet i kommuner, landsting och regioner)

<sup>12</sup> The Swedish Trade Union Confederation in Sweden 2010. Vulnerable on several fronts (Landstingsorganisationen i Sverige 2010 Utsatta från flera håll)

<sup>13</sup> Annuities due to work injuries 2006

<sup>14</sup> SOSFS 2009:22 General advices on Social Services Committee's work with women who are victims of violence and their children who have witnessed violence. (SOSFS 2009:22 Allmänna råd om socialnämndens arbete med våldsutsatta kvinnor med barn som bevittnad våld.)

<sup>15</sup> Proposition 2009/10:232: Strategy to strengthen children's rights

<sup>16</sup> National Board of Health and Welfare 201 Föräldrarstöd för familjer där barn eller vårdnadshavare har en funktionsnedsättning

<sup>17</sup> Save the Children reports

[http://www.rb.se/press/pressmeddelanden/Pages/Barnfattigdom\\_i\\_Sverige\\_ett\\_brott\\_mot\\_Barnkonventionen.aspx](http://www.rb.se/press/pressmeddelanden/Pages/Barnfattigdom_i_Sverige_ett_brott_mot_Barnkonventionen.aspx)

<sup>18</sup> The National Board of Health and Welfare april 2010 Barn som har utvecklingsstörda föräldrar. Artikelnr:2007-131-8

<sup>19</sup> The National Association of the Deaf and Hard of Hearing annual report 2007, Äh det var inget viktigt...

<sup>20</sup> From the report Hur kommer barn till tals hos er? Project Egen Växtkraft 2011

<sup>21</sup> <http://www.hjarnkoll.se/Hur-kan-du-bidra/>

<sup>22</sup> The School Inspectorate, skolsituationen för elever med funktionsnedsättning i gymnasieskolan 2010

<sup>23</sup> Delegation for Human Rights in Sweden, Y Brune, Svenska nyhetsmedier och mänskliga rättigheter i Sverige, en översikt SOU 2007:102 Rapport nr 1 Kalmar 2008. Länk till rapporten: <http://www.regeringen.se/sb/d/108/a/96279/dictionary/false>

- 
- <sup>24</sup> Ljuslinder, Karin. No one is normal at a closer look, Disability courses, Sveriges Television 1956-2000, Umea University Library 2002 (Ljuslinder, Karin På nära hall är ingen normal, Handikappdiskurser)
- <sup>25</sup> Joel Rasmussen Birgitta Höjer Orebro University – Mediebilden av psykisk sjukdom och psykiatri i samband med våldsbrott En studie av DN, Aftonbladet och Rapport
- <sup>26</sup> Handisam, Open comparisons of accessibility in government, questionnaire to authorities 2010
- <sup>27</sup> The Ministry of Education. Accessibility of school premises and freedom of choice for pupils with disabilities, 2006
- <sup>28</sup> Network Youth for Accessibility, survey of accessibility to 77 polling stations at the election 2010
- <sup>29</sup> Government white paper 2009/10:166. Uppföljning av den nationella handlingsplanen för handikappolitiken och grunden för en strategi framåt Skr:2009/10:166, 2010
- <sup>30</sup> The Swedish Arts Council, Uppföljning av enkät om tillgängligheten i kulturlivet, 2009
- <sup>31</sup> Banverket(Swedish Transport Administration) upplevd tillgänglighet till transportsystemet för personer med rörelsehinder, resor med tåg,2010
- <sup>32</sup> Inquiry on victims of sexual offences, claim and inquiry on sexual crimes, proposals on improvements based on a crime victims perspective, a memorandum by the Ministry of Justice, 2005 page 65.
- <sup>33</sup> The National Board of Health and Welfare, Accessibility from the perspective of disability. En undersökning bland socialkontor och vårdcentraler, sid 9
- <sup>34</sup> The National Board of Health and Welfare, Tillgänglighet ur ett funktionshindersperspektiv. En undersökning bland socialkontor och vårdcentraler sid 9
- <sup>35</sup> The National Board of Health and Welfare, Alltjämt ojämnt – Levnadsförhållanden för vissa personer med funktionsnedsättning
- <sup>36</sup> Handisam, Swedish Agency for Disability Policy Coordination , Rätt från Början – underlag för e-inkludering 2009
- <sup>37</sup> The National Board of Health and Welfare, Öppna jämförelser och utvärdering 2010 – Psykiatrisk vård –ett steg på vägen, 2010 sid 17
- <sup>38</sup> Report from the National Institute of Public Health 2009, Stockholm, National Board of Health and Welfare; 2009
- <sup>39</sup> The Swedish Civil Contingence Agency, årlig uppföljning 2009
- <sup>40</sup> <http://-sosararm.se/sv/112/Att-larma-112/Satt-att-larma/-Larma-112-via SMS/>
- <sup>41</sup> The National Board of Health and Welfare, Tillgänglighet ur ett funktionshindersperspektiv – en undersökning bland socialkontor och vårdcentraler 2010 s 10
- <sup>42</sup> National Council for Crime Prevention, Våld mot personer med funktionshinder, Olle Westlund 2007
- <sup>43</sup> Association of Women Attorneys, Jönköping 2009
- <sup>44</sup> Swedish Research Institute for Disability Policy, Handu, Mäns våld mot kvinnor med funktionshinder 2007
- <sup>45</sup> HIV and Punishment – an unsolved problem, Peter Gröön och Madelaine Lejonhuvud, Svensk Juristtidning, s 609
- <sup>46</sup> Auris, “Hörde inte sin dom” nummer 2 2010([www.hrf.se/upload/3662/Auris1002,s4-5](http://www.hrf.se/upload/3662/Auris1002,s4-5))
- <sup>47</sup> [http://www.humanrights.gov.se/extra/faq/?module=instance=3&action=question&show&id=2835&category\\_id=ee](http://www.humanrights.gov.se/extra/faq/?module=instance=3&action=question&show&id=2835&category_id=ee)
- <sup>48</sup> Attention Deficit Hyperactivity Disorder (ADHD) among longer-term prison inmates is a prevalent, persistent and disabling disorder. Ylva Ginsburg et al Stockholm 2010 doi.10.1186/1471-244X-10-112 (<http://www.biomedcentral.com/content/pdf/1471-244x-10-112.pdf>)
- <sup>49</sup> <http://sverigesradio.se/sida/gruppsida.aspx?programid=3437&grupper=7767>

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- <sup>50</sup> Published February 4<sup>th</sup> 2008, 00.53. [http://www.svd.se/nyheter/inrikes/barn-blir-inlasta-bland-sjuka-vuxna\\_832347.svd](http://www.svd.se/nyheter/inrikes/barn-blir-inlasta-bland-sjuka-vuxna_832347.svd)
- <sup>51</sup> County Administrative Board in Västernorrland 2009: Kartläggning av förekomst of hot ovh våld I verksamheter enligt LSS och SOL Västernorrlands län 2006-2007
- <sup>52</sup> County Administrative Board, Uppsala 2009: Kartläggning av förekomst av hot och våld I verksamheter enligt LSS och SOL Uppsala län 2006-2007
- <sup>53</sup> ECT treatment – a pilot study. National Board of Health and Welfare 2010 ISBN 978-91-86585-14-3
- <sup>54</sup> The National Board of Health and Welfare 2009, Att uppfylla samhällsansvaret , förbättrat kunskapsstöd när det gäller socialtjänstens arbete med våldutsatta kvinnor och barn som bevittnat våld
- <sup>55</sup> The national Council for Crime Prevention 2010 Mäns våld mot kvinnor, hedersrelaterat våld och förtryck samt våld i samkönade relationer, En första uppföljning av regeringens handlingsplan
- <sup>56</sup> AA page 9
- <sup>57</sup> County Councils and The National Board of Health and Welfare, 2008-2009 Våldutsatta kvinnor och barn som bevittnat våld – alla kommuners ansvar slutrapport från en nationell tillsyn.
- <sup>58</sup> The Swedish Authority of Local Authorities and Regions 2009 Utveckling pågår, en kartläggning av kvinnofridsarbetet I kommuner och landsting och regioner.
- <sup>59</sup> The National Council for Crime Protection, Report 2007:26 Våld mot personer med funktionshinder
- <sup>60</sup> The National Council for Crime Protection, Report 2007:26
- <sup>61</sup> The National Council for Crime Protection, Uppsala University 2001 Fritzes offentliga publikationer ISBN 91-973223-7-7, Slagen Dam, Mäns våld mot kvinnor I jämställda Sverige
- <sup>62</sup> Research Institute Handu 2007 Mäns våld mot kvinnor med funktionsnedsättning
- <sup>63</sup> AA page x
- <sup>64</sup> The national Board of Health and Welfare, 2005, page 32 Våld mot kvinnor med psykiska funktionshinder – förekomst, bemötande och tillgänglig stöd,
- <sup>65</sup> Stockholm's County Administrative Board Josefin Grände, 2010 Vägen till att se och agera – om våldutsatta kvinnor med funktionsnedsättning
- <sup>66</sup> Research Institute Handu Stockholm 2005 Levnadsnivåundersökning, en rapport om levnadsnivån för rörelsehindrade, hörselskadade, döva, synskadade personer
- <sup>67</sup> Government bill 1992/93:159 Stöd och service till vissa funktionshindrade
- <sup>68</sup> Barbro, Lewin, Who cares, Crime victims with disabilities, 2002 page 103 (Barbro Lewin, Vem bryr sig, Brottsoffer med funktionshinder, 2002 page 103)
- <sup>69</sup> Kubis 2002
- <sup>70</sup> The Swedish Board of Housing, Building and Planning som sektorsmyndighet inom handikappolitiken(The Board of Housing etc and the Handicap Movement)
- <sup>71</sup> Handu's survey on standards of living for deaf blind persons, 2007 (Handus levnadsnivåundersökning för dövblinda, 2007)
- <sup>72</sup> Handus living survey for deaf blind persons, 2007 (Handus levnadsundersökning för dövblinda, 2007)
- <sup>73</sup> The Swedish Transport Administration 2010, upplevd tillgänglighet till transportsystemet för personer med rörelsehinder resor med tåg
- <sup>74</sup> Special transport service and inter-municipal transport service 2009 Statistik 2010:8 Trafikanalys sid 17
- <sup>75</sup> Ibid s 15
- <sup>76</sup> Swedish Radio Jönköping 10<sup>th</sup> August 2010 Olika bedömningar I kommuner om vem som får färdtjänst <http://sverigesradio.se/sida/artikel.aspx?programid=91&artikel=3022706>

- 
- <sup>77</sup> Swedish Radio, P3, Kaliber, 19<sup>th</sup> November 2006: Träna idag eller fika på onsdag? Om färdtjänstens olika villkor.  
<http://sverigesradio.se/sida/artikel.aspx?programmet=1316&artikel=1040981>
- <sup>78</sup> The Swedish Transport Administration October 2009 Kvalitet inom färdtjänsten. En kvalitativ studie. sid 4-5
- <sup>79</sup> Ibid, sid 6
- <sup>80</sup> Ibid sid 11
- <sup>81</sup> Ibid sid 44
- <sup>82</sup> Disability ombudsman, publication 2001:9 Preliminär slutrapport över färdtjänstens tillstånd och utveckling samt behov av tillsynsmyndighet
- <sup>83</sup> Follow-up of the objectives for each section of the special transport service in 2005
- <sup>84</sup> Verva's questionnaire can be found at: <http://verva.24-timmarswebben.se/master.html?>
- <sup>85</sup> The National Board of Health and Welfare 2010 Alltjämt ojämligt – Levnadsförhållanden för vissa personer med funktionsnedsättning. sid 10
- <sup>86</sup> National Board of Health and Welfare 2006 Social rapport
- <sup>87</sup> National Board of Health and Welfare 2010 Social rapport sid 160
- <sup>88</sup> National Board of Health and Welfare 2004 Livssituationen två år efter stroke. En uppföljning av strokedrabbade och deras närstående.
- <sup>89</sup> Spouses of first-ever stroke patients: psychological well-being in the phase after stroke, Forsberg-Wärleby G, Moller A, Blomstrand C 2001 32(7):1646-51
- <sup>90</sup> Halmstad Institute of Education 2010 Centre for research on welfare, health and sport: Levnadsvillkor idag och jämförelser med 1990-talet. En studie om barn, unga, vuxna med utvecklingsstörning och autism samt vuxna med förvärvat hjärnskada I Halmstad kommun Eriksson H&Tideman M
- <sup>91</sup> Ibid sid 33
- <sup>92</sup> Ibid sid 74
- <sup>93</sup> Adoption Handbook for social services. National board of health and welfare Artikelnr-101-5 Västerås 2008 sid 70
- <sup>94</sup> Ibid sid 71
- <sup>95</sup> Modern adoption rules SOU 2009:61 Stockholm 2009
- <sup>96</sup> Ibid sid 102, 119-120
- <sup>97</sup> Stiletan nr 2 2010 sid 15-18 Godtycke vid adoption Nedladdad 2010-12-22
- <sup>98</sup> The Adoption Society Friends of the Children skriver om kraven:  
<http://www.bvadopt.se/scripts/lander.asp?ids=12&title=Kina> Nedladdad 2010-12-22 Även Adoptionscentrum skriver om Kinas nya adoptionskrav (2010-08-05):  
<https://www.adoptionscentrum.se/sv/Adoption/landerna/Kina/Adoption/.Nedladdad> 2010-12-22
- <sup>99</sup> National Board of Health and Welfare: Alltjämt ojämligt – Levnadsförhållanden för vissa personer med funktionsnedsättning
- <sup>100</sup> National Board of Health and Welfare Alltjämt ojämligt – Levnadsvillkor för vissa personer med funktionsnedsättning 2010
- <sup>101</sup> National Board of Health and Welfare april 2010 Barn som har utvecklingsstörda föräldrar Artikelnr 2007-131-8
- <sup>102</sup> National Board of Health and Welfare 2009 Artikelnr 2009-126-182 Barnens rätt och LVU Publicerad på [www.socialstyrelsen.se](http://www.socialstyrelsen.se), juni 2009 sid 30
- <sup>103</sup> The Ministry of Education lägesbedömning 2009 sid 61 ff
- <sup>104</sup> The Education Act chap.10, paragraph 30
- <sup>105</sup> The Ministry of Education I Lägesbedömning 2009, Förskoleverksamhet, skolbarnomsorg, skola och vuxenutbildning, rapport 337, 2009, s 16

- 
- <sup>106</sup> The Ministry of Education. Tillgänglighet till skolors lokaler och valfrihet för elever med funktionsnedsättning 2008
- <sup>107</sup> The National Board of Housing etc and the Swedish Energy Agency Kartläggning av inomhusmiljö och energi I skolor och förskolor 2007, STIL2
- <sup>108</sup> Swedish Schools Inspectorate, skolsituationen för elever med funktionsnedsättningar I gymnasieskolan
- <sup>109</sup> The Disability Movement :rapport 2007 s 55 <http://www.hrf.se/upload/pdf/rapport07.pdf>
- <sup>110</sup> The Schools Inspectorate:rapporter: "Skolsituationen för elever med funktionshinder I grundskolan" och "...gymnasiet"
- <sup>111</sup> The Disability Movement: rapport 2007 s 55 <http://www.hrf.se/upload/pdf/rapport07.pdf>
- <sup>112</sup> Annex 1 The Disability Movement: brev till utbildningsutskottet abg ny skollag 2009
- <sup>113</sup> Annex 2 The Disability Movement brev RRC som uppdrag
- <sup>114</sup> The Schools Inspectorate, Undervisning I svenska grundsärskolan, 2010
- <sup>115</sup> aa
- <sup>116</sup> The Ministry of Education, Lägesbedömning 2009, Förskoleverksamhet., skolbarnomsorg, skola och vuxenutbildning rapport 337, 2009, sid 10
- <sup>117</sup> Swedish National Institute of Public Health Arnholm Y, Onödig Ohälsa Hälsoläget för personer med funktionsnedsättning, Östersund 2008
- <sup>118</sup> Swedish National Institute of Public Health Nationella folkhälsoenkäten – Hälsa på lika villkor Östersund, 2008
- <sup>119</sup> National Association of the Blind Rapport om synskadades hälsa med data från Folkhälsoinstitutet, Enskede 2008
- <sup>120</sup> Swedish National Institute of Public Health, Arnholm, Y, Onödig ohälsa, Hälsoläget för personer med funktionsnedsättning, Östersund, 2008, sid. 8
- <sup>121</sup> National Board of Health and Welfare Alltjämt ojämnt – levnadsförhållanden för vissa personer med funktionsnedsättning 2010
- <sup>122</sup> Socialstyrelsen, Tillgänglighet ur ett funktionshindersperspektiv – En undersökning bland socialkontor och vårdcentraler, 2010.
- <sup>123</sup> The Advisory Board for Rehabilitation's report, SOU 2010:58. Stockholm, 2010, s 15
- <sup>124</sup> The National Board of Health and Welfare, Tillgång till habilitering och rehabilitering för personer som har insatser enligt LSS. Rapport till regeringen, 2007 s 12
- <sup>125</sup> Handu, Survey of Living Conditions
- <sup>126</sup> CI teams investigate, operate and rehabilitate patients with cochlea implants. CI teams usually consist of ear surgeons, audiologists, audionoms, councillors, speech therapists and hearing technicians
- <sup>127</sup> The Swedish Association for Persons with Difficulties Reading and Writing/Dyslexia , Enkät om förskrivning av hjälpmedel, Solna, 2010.
- <sup>128</sup> Handu, Survey of Living Conditions- personer med dövblindhet svarar, 2007
- <sup>129</sup> Swedish Institute of Assistive Technology, statistik på hörselområdet, 2009,2010
- <sup>130</sup> Swedish Institute of Assistive Technology, Kognitiva hjälpmedel – Nationell uppföljning av hjälpmedelsförsörjning för personer med kognitiva funktionsnedsättningar, 210
- <sup>131</sup> Swedish disability policies state that UN standard rules are guidelines. If FK had complied with the action plan and standard rules the woman would have been able to get the job.
- <sup>132</sup> Statistics Sweden Funktionsnedsattas situation på arbetsmarknaden, 4 e kvartalet 2008 Stockholm 2009
- <sup>133</sup> AA
- <sup>134</sup> National Board of Health and Welfare, alltjämt ojämnt -levnadsförhållanden för vissa personer med funktionsnedsättning 2010
- <sup>135</sup> AA

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- <sup>136</sup> The Social Insurance Office, Diagnosmönster i förändring – nybeviljade förtidspensioner, sjukersättningar och aktivitetsersättningar 1971-2005, 2007
- <sup>137</sup> The National Board of Health and Welfare, Daglig verksamhet enligt LSS – en kartläggning, 2008.
- <sup>138</sup> The National Board of Health and Welfare, Alltjämt ojämlikt – Levnadsförhållanden för vissa personer med funktionsnedsättning, 2010
- <sup>139</sup> The National Board of Health and Welfare -Levnadsförhållanden för vissa personer med funktionsnedsättning 2010
- <sup>140</sup> Statistics Sweden, labour market situation for persons with disabilities, Q4 2008, Stockholm 2009.
- <sup>141</sup> Questionnaire at [http://.samhall.se/templates/news\\_1668.asp](http://.samhall.se/templates/news_1668.asp)
- <sup>142</sup> The Social Insurance Office, Diagnosmönster i förändring – nybeviljade förtidspensioner, sjukersättningar och aktivitetsersättningar 1971-2005, 2007
- <sup>143</sup> The Advisory Board for Rehabilitation's report SOU 2010.58, 2010
- <sup>144</sup> The National Board of Health and Welfare, Alltjämt ojämlikt – Levnadsförhållanden för vissa personer med funktionsnedsättning
- <sup>145</sup> Statistics Sweden Hushållens ekonomi, 2008.
- <sup>146</sup> Swedish National Institute of Public Health folkhälsoenkät 2005
- <sup>147</sup> 2009 National Board of Health and Welfare and Karolinska Institute Miljöhälsorapport
- <sup>148</sup> The Swedish Board of Housing, Building and Planning, regulations: "Boverket Handbok BAB". Under punkt 6.7.11 sägs "Bidrag lämnas inte till elsanering" Man hänvisa till yttrande av Socialstyrelsen av den 21 november 1991 (32-8200/91) och en rapport (dnr 32-9581/95) samt ett regeringsbeslut 1992 11 19, dnr 92/7724J
- <sup>149</sup> Local Government Act . SFS 1991:900,4 kap 33§
- <sup>150</sup> Handu's survey of standards of living for deaf-blind, 2007
- <sup>151</sup> The National Board of Health and Welfare, Alltjämt ojämlik – levnadsvillkor för vissa personer med funktionsnedsättning, 2010
- <sup>152</sup> The Swedish Arts Council, nya kulturvanor, kulturen i siffror, 2008
- <sup>153</sup> Swedish Arts Council. Uppföljning av enkät om tillgängligheten till kulturlivet 2009
- <sup>154</sup> The Stockholm Arts Council, Kulturrådet – en lägesrapport, Inledningsanförande av Benny Marcel, Öppen utfrågning I riksdagen om funktionshindrade och scenrummet 12 november 2009
- <sup>155</sup> Law (SFS 1960:729) Om uphovsrätt till litterära och konstnärliga verk
- <sup>156</sup> The Schools Inspectorate, Mycket idrott och lite hälsa. Skolinspektionens rapport från den flygande tillsynen i idrott och hälsa 2010, sid 4
- <sup>157</sup> Consumer Agency, Marnadskontroll av lekplatser, rapport 2008: 15, 2008

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## **This is the Swedish disability movement’s alternative report to the UN Committee on the Rights of Persons with Disabilities**

The report is a complement to the first official report by the Swedish Government to the UN Committee.

The aim of the report is to provide an overall view of how Sweden complies with the Convention’s rights for girls, boys, women and men with disabilities. Each article includes:

- Description of the regulation
- Disability movement’s views on the regulation
- Statistical comparisons and research results
- Disability movement’s views on the factual situation
- Disability movement’s recommendations on what needs to be done by the Swedish Government in order to better comply with the rights

The report has been prepared by the project “Agenda 50 – tools for our rights”



Swedish Disability Federation, Box 1386, 172 27 Sundbyberg, Sweden  
Telephone +46 8 546 404 00, [www.handikappforbunden.se](http://www.handikappforbunden.se)