

**The Swedish Disability Movement's
alternative report**

on

**UN International Covenant on
Economic, Social and
Cultural Rights**



SWEDISH DISABILITY FEDERATION

Collector of facts: Annika Åkerberg
Translation into English: ComText – InterLingua AB
SWEDISH DISABILITY FEDERATION 2006

The Swedish disability movement's alternative report relating to the Covenant on Economic, Social and Cultural Rights

This is the Swedish disability movement's report relating to the Covenant on Economic, Social and Cultural Rights, adopted at the Swedish Disability Federation's annual meeting in May 2006.

The object of this report is to give the committee a comprehensive idea of what the situation is like for people with disabilities in Sweden. Via this report, we also wish to set out the disability movement's recommendations on what measures the Swedish Government should take to enable Sweden to better observe economic, social and cultural rights.

The report should be seen as complementing Sweden's fifth official report relating to the Covenant on Economic, Social and Cultural Rights. The report follows the "Revised general guidelines regarding the form and content of reports to be submitted by states parties under articles "16 and 17" of the international covenant on economic, social and cultural rights" in order to ease comparison between the reports.

Civil society in Sweden intends sending another alternative report. The other alternative report deals with the situation of other groups within society. The two alternative reports therefore complement one another.

In total, 57 organisations of people with disabilities are behind this report, see Annex 3.

The report was submitted to the Swedish Government, May 22, 2006.

May 2006

THE SWEDISH DISABILITY FEDERATION

Ingemar Färm
Chairman

Table of contents

Introduction

Organisation of the report

Background information

Discrimination

The national action plan for human rights

Action plan for disability policy

Supervision by ombudsmen and their role

Local and regional autonomy

Action plans – a natural tool

Influence and impact

Support and service

Accessibility

Attitudes and treatment

Statistics

Conclusions

Article 2

- 1 Summary information
- 2 Discrimination legislation in Sweden
 - 2.1 Introduction
 - 2.2 The Working Life Discrimination Act
 - 2.3 The Equal Treatment of College Students Act
 - 2.4 The Discrimination Prohibition Act
 - 2.5 The Act Prohibiting Discrimination and other Mistreatment of Children and Pupils Act
 - 2.6 Need for extended discrimination protection
- 3 Proposal for new Discrimination Act
- 4 Antidiscrimination clauses in public procurement
- 5 Conclusions and recommendations

Article 3

- 1 Swedish equality policy
- 2 Rights from an equality perspective
- 3 Conclusions and recommendations

Article 6

- 1 Work and employment
- 2 Unemployed young people
- 3 Negative attitudes and treatment – primary reasons for exclusion
- 4 Guidance and employment service
- 5 Labour market policy measures
- 6 The social insurance office's initiatives and occupational rehabilitation
- 7 Employers' co-financing responsibility
- 8 The State as employer
- 9 Conclusions and recommendations

Article 7

- 1 Equal pay for equal work
- 2 Adapted work conditions
- 3 Distribution of responsibility
- 4 Conclusions and recommendations

Article 8 -

Article 9

- 1 Introduction
- 2 Sickness benefit
- 3 Activity and sickness compensation
- 4 Disability allowance
 - 4.1 Treatment
 - 4.2 Several levels
- 5 The situation for elderly people with disabilities
- 6 Economic support for families
 - 6.1 Temporary childcare benefits
 - 6.2 Home care allowance
- 7 Conclusions and recommendations

Article 10

- 1 Support for families**
 - 1.1 Support under the law
 - 1.2 Deficiencies in the system
 - 1.3 Decisions not implemented
- 2 Violence against children with disabilities**
- 3 Violence against adults with disabilities**
 - 3.1 Vulnerability to violence
 - 3.2 Women with mental disabilities
 - 3.3 Lack of support initiatives after abuse
 - 3.4 Reporting of crime and the legal process
- 4 Conclusions and recommendations**

Article 11

- 1 Standard of living of people with disabilities**
- 2 Food**
- 3 Housing**
 - 3.1 Housing and assistance
 - 3.2 Homelessness
 - 3.3 Institutions and special homes
 - 3.4 Adequate housing
 - 3.5 Statistics on people "dependent on help"
 - 3.6 Decisions not implemented
 - 3.7 Lack of competent personnel
- 4 Assistive devices**
- 5 Conclusions and recommendations**

Article 12

- 1 Standard of health**
 - 1.1 Introduction
 - 1.2 Statistics
- 2 Healthcare and medical treatment**
 - 2.1 Geographical changes
 - 2.2 National guidelines
 - 2.3 Lack of compliance with laws and agreements
 - 2.4 Some particularly vulnerable groups
 - 2.5 Specialist care

- 3 Habilitation and rehabilitation
- 4 Lack of co-ordination
- 5 Conclusions and recommendations

Article 13

- 1 Primary education
- 2 Secondary education
- 3 Deficiencies in compulsory and upper secondary school education
- 4 Special schools and hearing classes
- 5 Special schools
 - 5.1 A lack of resources in compulsory school
 - 5.2 Upper secondary special schools
- 6 Colleges and universities
- 7 Local authority adult education
- 8 Education for adults with intellectual disabilities
- 9 Adult education colleges
- 10 Free schools
- 11 Right to choose schools
- 12 Lack of competence on the part of teachers and principals
- 13 Conclusions and recommendations

Article 15

- 1 Culture
 - 1.1 Introduction
 - 1.2 Culture for children
 - 1.3 Participation of adults in cultural life
 - 1.4 The cultural institutions' accessibility work
 - 1.5 Media
 - 1.6 The information society
- 2 Science
 - 2.1 Disability research
 - 2.2 Disability history – cultural history

3 Conclusions and recommendations

ANNEX 1 Summary of the report

ANNEX 2 Summary of the recommendations

ANNEX 3 Organisations of people with disabilities that support the report

ANNEX 4 List of abbreviations

ANNEX 5 Footnotes in Swedish

Introduction

The prime reason why the Swedish Disability Federation has chosen to draw up an alternative report is that we want to draw attention to the fact that full participation and equality have not been achieved in Sweden for people with disabilities. Another reason is the absence of a disability perspective both in previous reports from the Swedish Government and in the committee's concluding observations. The Swedish Disability Federation considers that issues relating to human rights for people with disabilities should be highlighted as a natural part of both the Swedish political process and also in the UN's monitoring system.

Through this report, we wish to contribute to girls, boys, women and men with disabilities in Sweden having their economic, social and cultural rights respected and the social systems being further developed in accordance with the recommendations presented. We also hope that we can inspire the disability movement in other countries to produce their own reports.

Organisation of the report

The report starts with a section of background information on disability policy in Sweden, a description of areas that affect all the rights in the Convention and also some statistics and a description of what groups of people are covered by the term "people with disabilities" in Sweden.

The main chapter of the report deals with all the rights articles in the Convention, with the exception of articles 1, 4, 5 and 14. All articles contain a description of the situation in the country. Each main caption is followed by a section on what the Swedish Disability Federation thinks about the situation. At the end of each article is a list of what recommendations the Swedish Disability Federation gives the State on how the situation could be improved in Sweden and to allow an improvement in Sweden's observance of the Convention's articles. To facilitate an overview of the Swedish disability movement's recommendations, a summary of all the recommendations is also appended. For footnotes in Swedish, see annex 5.

Background information

Discrimination

A ban on discrimination on grounds of disability is set out in the Swedish Constitution. The provisions of the Constitution cannot be referred to the courts, but no other laws or ordinances may conflict with its provisions. For more information on the situation and the laws in this country relating to discrimination, see article 2.

General welfare

The approach of Swedish welfare policy can principally be regarded as general, which means that the public services systems and social insurance systems are aimed at the entire population and not just "the needy".

The ban on discrimination and general welfare form two important parts of the Swedish system.

The national action plan for human rights

In Spring 2006, the Swedish Government presented the second national action plan for human rights (for the period 2006 – 2009). The plan is intended to provide guidelines and a structure for human rights work and in this way speed up the implementation of the rights. The proposed measures in the action plan are aimed at the entire public administration, at national, regional, local council and municipal level and are based on various discrimination grounds, such as sex, ethnic background, religion or other conception of faith, sexual orientation and disability.

Action plan for disability policy

In 1999, the Swedish Government adopted a national action plan for the disability policy "From patient to citizen" (government bill 1999/2000:79). The action plan extends until the year 2010 and involves all areas of society. Disability policy work is to be specifically geared to identifying and eliminating obstacles to full participation in society for people with disabilities, preventing and combating discrimination and giving children, young people and adults with disabilities opportunities for achieving independence and self-determination. Until 2010, three areas of work are specifically prioritised:

- ensuring that a disability perspective permeates all sectors of society
- creating an accessible society
- improving the treatment of people with disabilities

The national action plan gives the national authorities clearer responsibility than in the past for disability policy work. Fourteen authorities have been designated as "sector authorities" with specific responsibility for implementing disability policy within their respective areas of society. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities for ensuring the participation and equality of people with disabilities underlie disability policy.

A new authority, "The authority for disability policy co-ordination" (Handisam), was established on 1 January 2006. This authority's task is to promote effective implementation of the national action plan. The work entails, among other things, taking responsibility for the co-ordination of disability policy measures by supporting and encouraging players at various levels to consider disability policy targets in their respective activities.

Supervision by ombudsmen and their role

There are 5 different ombudsmen in Sweden: the Equality Ombudsman, the Ombudsman for preventing ethnic discrimination, the Swedish Disability Ombudsman (SDO), the Ombudsman for preventing discrimination on grounds of sexual orientation and the Children's Ombudsman, whose tasks include monitoring human rights issues and countering discrimination.

The task of the Swedish Disability Ombudsman (SDO) under the law (SFS 1994:749) is to monitor issues concerning the situation for people with disabilities. Private individuals can approach the Swedish Disability Ombudsman for advice and to report that they have suffered discrimination. The Swedish Disability Ombudsman can then undertake an investigation of the case. In cases where discrimination arises, the Swedish Disability Ombudsman can try to achieve mediation between the parties or

to refer the matter to the courts. What reports are made to the Swedish Disability Ombudsman are set out in article 2.

Local and regional autonomy

In Sweden, local authorities and county councils are responsible for ensuring that many of the economic, social and cultural rights that exist are observed in practice. A local authority represents not only a legal entity but also the geographic area that forms the local authority and also a municipal autonomous body. Municipal autonomy is a concept that is firmly enshrined in the Swedish legal tradition. It is often defined as a principle that indicates the relationship between the State and the local authority and that is intended to give local authorities an independent right of determination that is unconstrained within certain limits.¹ Municipal autonomy has been constitutionally enshrined in the Constitution since 1974. The latter also lays down the "Legality principle", i.e. the fact that public authority is exercised under the laws. The laws that govern the local authorities are thus the rules that indicate the framework for municipal autonomy.

Action plans – a natural tool

At not only national but also regional and local level, action plans are a natural tool for ensuring continuing progress in all sectors of society. There are a number of action plans at various levels and areas in Swedish society, although these action plans are often independent. The disability movement's position is that all policy areas have a disability aspect to them.

The disability movement's intention is for this report and also the Committee's comments to help ensure that all action plans highlight and address the disability perspective.

Influence and impact

Disability policy boards exist in the vast majority of local authorities and county councils. The boards consist of representatives of the disability movement and the local authority or the county council. The board has the task of safeguarding the interests of the people with disabilities in the local authority's/county council's planning. The Swedish Disability Federation considers that the thinking behind the disability policy boards is sound but that this form of user influence should be viewed as a natural part of professional activity and requires guidelines, resources, training and follow-up.

The Swedish Disability Federation would stress that user influence is important when both policy-related and individual decisions are taken. Various kinds of user influence are common in Swedish local authorities and county councils. More than 90 per cent of local authorities have some kind of user influence². Despite this, there are only 23 per cent of the local authorities that meet the requirements for user influence under the supervision of the National Board of Health and Welfare and the county

¹ Nilsson, Frida, Municipal court defiance – the conflict between municipal autonomy and the legality principle, Lund University, Legal Faculty, 2005

² Ds 2001:34, Experience of widespread user influence

administrative boards. Various forms of consultation represent the commonest form of user influence. The use of special bodies in which users can be given greater influence, namely self-administration bodies, is, however, rarer.³ User participation in quality work and activity development in social services takes place on a very small scale. User influence/participation in research exists to only a limited extent and user participation/influence in, for example, qualified social worker training usually consists only of occasional visits by individuals with user experience. In relation to user investigations, these are conducted in most local authorities. In the case of activities for the elderly, they are also considered to be recurrent and a natural part of ongoing quality work. With regard to individual and family care, the overall impression is, on the other hand, that users' views are not continually and systematically sought.⁴

The Swedish Disability Federation makes the following demands of the responsible authorities:

* Local authorities and county councils should observe the obligations imposed on them by laws and guidelines and, in collaboration with local user groups, formulate strategies on how effective user influence can be further developed. The support for local user associations should be developed and user audits conducted.

* The confederations of local authorities and county councils should, based on the deficiencies identified by, among others, the National Board of Health and Welfare, actively work on supporting development in local authorities and county councils.

Support and service

In Sweden, there are principally two different laws that regulate what support people should receive from society in being able to live independent lives (and given their human rights). The first law is the "Social Services Act" (SoL). SoL covers all people in society, both with and without disabilities. Assistance pursuant to SoL must provide reasonable living conditions. Assistance should be understood to mean: "support for provision and assistance for life in other respects". The local authority conducts an individual review of the applicant's needs. This might include, for example, help in cleaning, washing, shopping, cooking or other personal care.

For individuals with major disabilities that bring about significant difficulties in their everyday lives and thus an extensive need for support or services, there is the "Act on support and service for certain individuals with disabilities" (LSS 1993:387). This Act provides for ten different initiatives: advice and support, personal assistance and assistance replacement, companion service, contacts, relief service in the home, short-term stays outside the home, short-term supervision for school pupils over 12 years of age outside the home, foster homes or specially serviced housing for children and young people who need to live outside the parental home, specially serviced housing for adults or other specially adapted housing for adults and also daily activities for people of working age not in gainful employment and who are not receiving training.

³ Ds 2001:34, Experience of widespread user influence

⁴ User participation in social service skills development, the National Board of Health and Welfare 2003

In cases where individuals covered by the LSS require personal assistance for more than 20 hours a week, the Insurance Fund assumes responsibility for costs from the local authority. The compensation is called assistance compensation pursuant to the "Act on Assistance Compensation", LASS, (1993:389) and the "Assistance Compensation Order" (1993:1091).

The Swedish Disability Federation can verify that Sweden has good laws in terms of services for people with disabilities but that they often do not function in practice. This is dealt with specifically under articles 10 and 11.

Accessibility

Accessibility is central to all people with disabilities, not only for those with a mobility impairment and reduced orientation capacity. Accessibility also concerns groups such as people with allergies, brain injuries, hard of hearing, mental disabilities and difficulties with reading and writing. In addition, it does not concern purely physical ability to get on but also access to information and communication, (UN standard rule 5)

In Sweden, there is already strong legislation that is designed to make society more accessible. This is set out, among other things, in the "Planning and Building Act", which specifies that easily remedied obstacles in public buildings and in public places must be eliminated. The problem is that such legislation is not observed. Certain laws were enacted several decades ago. A concrete example is the Disability Adaptation of Public Transport Act, which was enacted in 1979. Nonetheless, a great deal has happened in 25 years.

Attitudes and treatment

Attitudes and treatment essentially means the fact that all should be respected as they are. This entails being allowed to live in an accessible society and not suffering discrimination. The national action plan for disability policy specifies that employees' treatment and ways of working are as important to increased accessibility as access to adapted information and physical environments. Treatment at the individual level is dependent on collective treatment, which is expressed in laws and other rules and in how they are interpreted and applied.

In Sweden, ignorance in society, negative special treatment, ostracism and bullying continue to be everyday problems for many people with disabilities. This leads in turn to such individuals, in contrast to people without disabilities, finding it harder to have their human rights respected in Swedish society.

In change-oriented work on something as complex as our values, it is important to try to define which institutions in society impart, and thus maintain, our values more strongly than others. It is of the utmost importance that awareness of rights, opportunities and needs for people with disabilities generally increases in Sweden. Greater awareness is also required for participation under equal conditions.

Statistics

In Sweden, we have a broad conception of what the term disability means. We would refer to the list of organisations that are behind this report and that form part of the Swedish disability movement. The starting point for determining who is considered to have a disability is the description of the UN Standard Rules and also the individual experience of the situation.

In relation to more traditional disabilities, national statistics from the Swedish Handicap Institute show that:

- 1.2 million Swedes are considered to have some form of permanent disability.
- Around 560 000 people over 16 years of age have mobility impairments. Of these, around 100 000 need a wheelchair.
- Just over 165 000 people over the age of 16 have impaired vision. Of these, around 23 000 are blind or severely visually impaired.
- Around 980 000 people are hard of hearing.
- 150 000 over the age of 16 are completely deaf or are severely hard of hearing.
- Around 36 000 people are calculated to have some form of intellectual disability.
- Around 2 000 000 people are estimated to have some kind of allergy.
- The proportion of people with disabilities and the severity of the disability increase with age. Between 2000 and 2020, the proportion of people over the age of 65 is expected to rise from around 17 per cent to close on 22 per cent. After 2020, the proportion of people over the age of 80 is expected to rise sharply.

The total population of Sweden in March 2006 was 9 047 752, with 4 561 202 women and 4 486 550 men.

Conclusions

Despite the intentions of the Swedish Government and Parliament, it will be a long while before Sweden can be considered to observe the rights set out in the Covenant on Economic, Social and Cultural Rights. According to the Standard Rules, for example, medical care, rehabilitation, support and service represent requirements for participation under equal conditions. In Sweden, good laws covering all these areas exist, but, as this report shows, the laws are not observed at local level in society. It is indefensible that people with disabilities do not have their rights respected owing to other priorities in a welfare state-based country like Sweden.

The disability movement's view is that the political will expressed verbally at national, regional and local level is very strong. However, when this will needs to be translated into practice, decision-making does not coincide with the political will. This is one of the main reasons for continued outsider status and discrimination continuing to be recurrent realities in Swedish welfare. This means that people with disabilities cannot fully exercise their rights and thus cannot discharge their obligations as members of society.

Article 2

1 Summary information

Despite the fact that the country has legal protection against certain forms of discrimination, discrimination for reasons of disability is common in Sweden. How the discrimination manifests itself is set out in the articles below. This chapter provides only some summary statistics. Relevant legislation is dealt with in the next section.

One in every two persons with disabilities feels that he/she is discriminated against! This is shown by a survey conducted in 2005 by Statistics Sweden on behalf of, among others, the Swedish Disability Ombudsman. In most cases, this involves experiences in everyday life. More than one in every four people state that they:

- cannot use buildings,
- cannot read information,
- cannot use aeroplanes/buses/trains.

Women with disabilities feel more highly discriminated against than men. Nearly 40 per cent of women feel discriminated against when purchasing goods or services. In healthcare and medical treatment, nearly one third feel discriminated against, while just over one quarter feel discriminated against in relation to public transport.

Younger people feel more discriminated against than the elderly. In cafés, restaurants and other places where people go out, younger people feel more vulnerable, with just over 40 per cent stating this. Just as many feel discriminated against when purchasing goods and services.

Nearly half of those who responded state that the discrimination involves being the object of derogatory comments and suffering bullying, teasing and ridicule.

2 Discrimination legislation in Sweden

2.1 Introduction

A ban on discrimination for reasons of disability is enshrined in the Swedish Constitution. The provisions of the Constitution cannot be referred to the courts; however, no other laws or ordinances may violate its provisions. To bolster the protection against discrimination further, there have since 1999 been four laws that prohibit discrimination for reasons of disability. These Acts relate to working life, training, the purchasing of goods and services, and housing.

2.2 The Working Life Discrimination Act

The first Act was adopted in 1999. This is an Act that prohibits discrimination in working life on grounds of disability. The Act applies, for example, to recruitment, wage-setting and the provision of notice of dismissal. An employer is not allowed to

treat someone seeking work or an employee worse owing to disability. An employer is also obliged to adopt supportive and adaptation measures in certain situations.

The Act was tightened up on 1 July 2003 and was extended to encompass professional practice as well. From solely protecting people with disabilities, people with links to someone with a disability are now also protected.

Since the Working Life Discrimination Act was passed, a number of settlements have been achieved between the Swedish Disability Ombudsman (SDO) and employers and between trade unions and employers. The Act was tested for the first time in court in 2003 when the Swedish Labour Court found that a man with diabetes had been discriminated against when he applied for a job at an oil refinery. The number of notifications is growing steadily. In 2004, the Swedish Disability Ombudsman received 81 notifications of discrimination in working life compared with 50 in 2003.

2.3 The Equal Treatment of College Students Act

The "Equal Treatment of College Students Act" has been in effect since 1 March 2002. The Act was the first one to ban discrimination for reasons of gender, ethnic background, religion, sexual orientation and disability in one and the same law. The object of the Act is to promote equal rights for students and applicants and to counter discrimination. Colleges must plan and document what measures are needed to promote equal treatment and prevent harassment.

The number of notifications of discrimination at college received by the Swedish Disability Ombudsman has fluctuated in recent years. In 2002, 9 notifications were received, while in 2003 25 notifications were received. In 2004, the number of cases fell to 12, while in 2005 11 notifications were received.

The area that predominates is accessibility. Accessibility cases account for 47 per cent of the number of notifications.

2.4 The Discrimination Prohibition Act

The third Act is the "Discrimination Prohibition Act". This Act was enacted in 2003 and stipulates that nobody should suffer inferior treatment on grounds relating to ethnic background, religion or faith, disability or sexual orientation. The Act protects individuals in the purchasing of goods and services and also when purchasing a home or in housing. The Act also contains a number of provisions relating to working life in the broad sense of the term. For example, it protects against discrimination in employment mediation and when starting up one's own business.

The discrimination reason of disability does not, however, apply in all sections of the Act. The areas not covered are social services, the subsidised transport service, the national subsidised transport service, home adaptation, social insurance, unemployment insurance, healthcare and medical treatment (sections 10-13).

According to the Swedish Disability Ombudsman's "wish list" for the discrimination committee, it is apparent that "it is the SDO's experience that negative special treatment of people with disabilities occurs within all the areas listed in sections 10-13." It is also apparent that many feel that they have inadequate opportunities for influence and self-determination, particularly within social services, healthcare and medical treatment. Unwarranted waiting times, ignorance and questioning of the

disability in question are some of the other problems faced by people with disabilities. A concrete example that can be cited is the problems surrounding abusers of people with mental disabilities ill who fall between two stools, and do not receive the care they need. It also happens that people with mental disabilities who seek care for somatic problems are referred to the psychiatry service. People with HIV feel that they are discriminated against by dentists who refuse to treat them. The same problem is experienced by people with intellectual disabilities, while people with mobility impairments have problems entering dental practices. Notifications concerning the Discrimination Prohibition Act increased during 2004. During 2004, 57 notifications were received by the Swedish Disability Ombudsman, compared with 25 in 2003. The Act is still relatively new and therefore not as well known as discrimination protection at work.

2.5 The Act Prohibiting Discrimination and other Mistreatment of Children and Pupils Act

This Act is the latest one and came into force on 1 April 2006. The Act prohibits discrimination for reasons of gender, ethnic background, religion, sexual orientation and disability. The Act covers all activities described in the School Act: preschool activity, schoolchildren care, compulsory schools, upper secondary schools and local authority adult education. The Act also means that children and pupils are afforded protection against other mistreatment, such as bullying. The Act stipulates that every school activity must have an equal treatment plan. The plan must describe what measures are planned to eliminate direct and indirect discrimination and other mistreatment. The plan must form an active tool that is used in day-to-day activities. If the obligation to draw up an equal treatment plan is not discharged, the principal becomes liable for damages.

If a pupil asserts that he or she has been the object of bullying and other mistreatment, the principal must investigate and prevent continued harassment. This applies also to offensive behaviour between the pupils.

The Swedish National Agency for Education and the various ombudsmen must, based on their areas of responsibility, ensure compliance with the Act.

When this alternative report is submitted to the Committee, the Act will just have come into force. The Swedish Disability Federation cannot therefore describe what impact the Act has had for people with disabilities.

2.6 Need for extended discrimination protection

The Swedish Disability Federation can state that there are two different shortcomings in the Swedish discrimination laws:

A. People with disabilities are not covered by all the provisions of the "Act Prohibiting Discrimination".

B. A lack of accessibility is a major reason why people with disabilities in Sweden cannot participate in society under equal conditions. Discrimination against individuals with disabilities owing to a lack of accessibility needs to be addressed in areas of society other than the world of work and colleges.

The Swedish Disability Federation considers that:

- Disability must be deemed to constitute discrimination in all sections and be subject to the same protection as other reasons for discrimination in the "Discrimination Prohibition Act".
- A lack of accessibility must be covered by the discrimination legislation.

3 Proposal for new discrimination Act

On 24 February 2006, a Discrimination Committee appointed by the Swedish Government presented a final report⁵ on discrimination legislation in Sweden. In the final report, the committee proposes, among other things, the introduction of a new Act relating to prohibition and other measures to combat discrimination. The new Act must in large part replace the current discrimination legislation, but also provide extended protection for more people and in a number of areas of society. The Act should have the object of countering discrimination and otherwise promoting equal rights and opportunities regardless of gender, sexual identity, ethnic background, religion or other faith, disability, sexual orientation or age. The Committee's point of departure has been that the protection against discrimination should be as equal as possible for the various grounds of discrimination.

The new Act relating to prohibition and other measures to combat discrimination proposes that failure to adopt accessibility measures is to be regarded as discrimination. In addition, it must not be possible to make any distinction between the various grounds of discriminations, as currently happens. This new Act may thus rectify some of the deficiencies that the disability movement considers to exist in current legislation in relation to people with disabilities.

The Discrimination Committee also proposes that the various ombudsmen be combined into a single authority, "the Discrimination Ombudsman". The new ombudsman is to supervise discrimination connected with the grounds of discrimination referred to above.

It is also proposed that the new Ombudsman be given independent authority to participate in the Government's reporting to the human rights treaty bodies. The Ombudsman must, under the proposal, also be granted authority to communicate independently with the treaty bodies.

The Swedish Disability Federation welcomes the fact that one of the Discrimination Committee's guiding principles has been that protection should be as equal as possible for the various grounds of discrimination. We also welcome the fact that it is proposed that lack of accessibility be covered by the new Act.

⁵ Government official report, SOU 2006:22, Coherent discrimination legislation

4 Antidiscrimination clauses in public procurement

Public procurement in Sweden amounts to SEK 300 billion per annum. Rules against discrimination may in this context play an important part in work to achieve equal rights in society.

The Swedish Disability Federation considers that:

- The Government must take greater responsibility for ensuring that antidiscrimination clauses are adopted in public procurement. Public funds should not be assigned to activities in which human rights are violated. The Swedish Government should investigate the possibility of linking State support to requirements of non-discrimination or active measures to promote diversity.

5 Conclusions and recommendations

Despite the fact that a ban on discrimination for reasons of disability is contained in both the Constitution and discrimination legislations, discrimination for reasons of disability is common in Sweden. It is of the utmost importance that the Swedish Government take the necessary steps to combat all forms of discrimination of girls, boys, women and men with functional impairments.

The Swedish Disability Federation recommends that the Swedish State:

- Review the discrimination legislation so that girls, boys, women and men with disabilities are given the necessary protection against discrimination.
- Work to ensure that a lack of accessibility comes to be classed as discrimination
- Ensure that anti-discrimination clauses are adopted in all public procurement.

Article 3

1 Swedish equality policy

The objective of Swedish equality policy must be for women and men to have the same rights, obligations and opportunities in all spheres of life⁶. In the government bill on equality policy entitled "Divided power – divided responsibility"⁷, the Swedish Government stated that equality should permeate all areas of policy and all activities.

This perspective is bolstered in the national action plan for disability policy, in which the Swedish Government also stated that the gender aspect is not catered for in relation to the field of disability. In a report issued by the National Board of Health and Welfare dating from 2004⁸, it is apparent that there is very little knowledge of whether men or women with disabilities are discriminated against on grounds of their gender. More recent studies of people with disabilities also often lack a gender perspective. People with disabilities are perceived in studies and research as "sexless". The National Board of Health and Welfare states that their living conditions are considered to be affected primarily by the disability.

In its communication to the Swedish Parliament in 2002 concerning follow-up of the action plan for disability policy, the Swedish Government declares that women and men do not achieve participation under the same conditions, that opportunities for influence are not the same for both sexes and that independence does not have the same meaning for women with disabilities as for men. It is further stated that the roles and living conditions of women and men differ in many ways. This means that rules, routines, assessments and interpretations of the law have differing consequences for women and men.

2 Rights from an equality perspective

From the information that we have nevertheless identified, we can, however, state that differences exist between how men and women with disabilities are treated in relation to all the rights in the Covenant on Economic, Social and Cultural Rights. This section deals with the rights from an equality perspective.

⁶ The Swedish Ministry of Industry, Employment and Communications, 2000, The Swedish Government's fifth periodic report of measures to implement the Convention on the Elimination of All Forms of Discrimination Against Women, p. 3.

⁷ The equality policy government bill, Divided power – divided responsibility (government bill 1993/94:147)

⁸ Equal Social Services? Gender perspective of social services, the National Board of Health and Welfare 2004

Article 6

As described in article 6, the gainful employment rate of people with disabilities is low. Studies show that of those in gainful employment, 82 per cent of men were in full-time work, as compared with 52 per cent of women.⁹ Women work part-time to a much greater extent than men. Considerably more men than women have protected work and jobs with pay contributions. Women receive compensation for illness and activity to a greater extent. The National Board of Health and Welfare states in its description of the situation of disability care dating from 2006 that men are thought to be the subject of work-oriented activity-enhancing initiatives more than women. In turn, women are more frequently the object of initiatives that replace various kinds of employment and work. As gainful employment is on the whole rare for people with disabilities, these women are at risk of being victims twice over. This situation also means that women have a substantially lower income from work.

Article 7

The Pay Contribution Report¹⁰ identified that fewer women than men receive the support they need to enjoy just and favourable conditions of work.

Article 9

The situation assessment by the National Board of Health and Welfare dating from 2002 states that the elements of the social insurance system that are based on income give more to men with disabilities than to women with disabilities. Women also have greater financial difficulties. In addition, it is stated that the social insurance provisions relating to economic compensation for illness and disability have differing effects for women and men and that work-related insurance provides better coverage for injuries that afflict men.¹¹

Article 10

Support for the family and also for adequate housing is covered by the LSS and SoL Acts. The National Board of Health and Welfare's description of the situation of disability care dating from 2004 shows that more men than women are the object of initiatives pursuant to LSS. The breakdown is roughly 60-40. Men and women are the object of the same kinds of initiatives pursuant to LSS, but women/girls are the object of more initiatives per person. More women are the subject of initiatives pursuant to SoL, above all in respect of home help. It is also apparent that differing consideration is taken of the joint responsibilities of spouses, which can lead to an unequal distribution of the support.

According to the Swedish action plan for equality, violence against women constitutes an obstacle to progress towards an equal society and to the individual women's legal security. In Sweden, violence against women in the home is a reality,

⁹ SOU 1998:138, Women, men and the physically impeded, p. 19. The figures are from a study conducted by SCB, the Swedish Disability Ombudsman and the Swedish Council for Working Life 1997.

¹⁰ The Pay Contribution Report, Government official report, Labour, 2003:95

¹¹ The Swedish Government's fifth periodic report to CEDAW – committee, 2002, Under article 11.1 e on Social security

but it is still a crime that is largely concealed. The violence occurs in all social classes, but welfare factors and disabilities affect the risk of being a victim.

Article 11

Handu's standard of living study dating from 2005 shows that women with disabilities have lower incomes than men. It is therefore more frequently women who lack a smallish cash reserve than men and who have had difficulties paying ongoing household expenses over the previous 12 months.

With regard to support for housing, it is apparent from the National Board of Health and Welfare report on the situation of disability care dating from 2006 that the proportion of men and women is very evenly split in terms of initiatives pursuant to LSS, except for contacts, housing for adults and daily activities, in which men are in the majority. Men also constitute a majority of those granted assistance compensation pursuant to LASS. More adult men than women receive personal assistance. Men also receive more hours of assistance. The gender differences are the same for all three groups of people within LSS. In terms of initiatives from players other than social services, too, there are gender differences. Men are, for example, more frequently given vehicle support, while women are more frequently granted subsidised transport.

The National Board of Health and Welfare report on the situation of disability care dating from 2004 criticises the fact that, though not great, the difference between men and women recurs systematically. However, despite the fact that women are given more home help, rehabilitation and early retirement than men, there are more women who do not receive full pre-retirement benefits or the help they need from the home help service.¹²

The number of initiatives for children with disabilities has grown since 1998, particularly for boys, who are more frequently the object of LSS initiatives than girls.

There are more women who use assistive devices, but they pay for them more frequently than men. There are more men than women who receive individually trialled assistive devices.¹³

Article 12

Women with disabilities more frequently consider their standard of health to be worse than men with disabilities.¹⁴ As shown by articles 6, 9 and 11, women often have lower income than men and therefore live in a more vulnerable economic situation. Many women testify to difficulties coping with ongoing expenses and the costs of necessary care and rehabilitation initiatives.

Women feel to a somewhat greater extent than men that they have been improperly or unfairly treated in terms of medical treatment.

¹² Government bill 1999/2000:79, p. 2

¹³ *Ibid*, p. 17

¹⁴ SOU: 1998:138, Women, men and disability, p. 13 *et seq.*

Men receive a greater share of the rehabilitation resources, more assistance compensation and find it easier to secure disability allowance than women with disabilities. Women use more medication than men, but the medicines prescribed to them are less expensive than those received by men.

The action plan for national disability policy highlights the fact that women live longer and have poorer health than men, which means that overall they need more help from society.

One study shows that women more frequently receive passive rehabilitation which entails sickness contributions with the lowest level of compensation, while men receive more active rehabilitation that is linked to work in the form of pay contribution services and training contributions.¹⁵

Article 13

In 2002, there were more boys than girls who attended special schools and secondary special schools. With regard to young people, SCB's study conducted in 2003 on living conditions for people with disabilities shows that it is more common for young men than for young women (16-24 years old) to study. We have unfortunately not been able to find any statistics on the gender distribution for pupils' school results.

Article 15

There is very little gender-specific information in the cultural sphere. In the extremely limited reflection of people with disabilities in the media, women and men are represented to the same extent in television programmes and features. Problems that primarily concern women with disabilities are that the media more frequently reinforce the prevailing stereotypes and that women are often ignored as sexual beings.¹⁶

The gender aspect is also conspicuous by its absence from disability research. Within disability research, we would therefore like to see studies with an equality perspective and, within gender and women's research, with a disability perspective.

3 Conclusions and recommendations

The Swedish Disability Federation can state that men and women, in Sweden, do not have equal right to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.

¹⁵ Katarina Piuva, 1999, Rehabilitation of the mentally long-term sicklisted – female and male subsystems within health insurance, Sex and power in social work, (ed.) Evy Gunnarsson & Astrid Sclytter, p. 73 *et seq.*

¹⁶ Ljuslinder, Karin, At close quarters no-one is normal, Disability discourses on Sveriges Television 1956 – 2000, Umea University Library, 2002.

The point of departure for the recommendations below is General comment no. 5, point 19 and General comment no. 16 in its entirety and also the objective in The Standard Rules. The objective of The Standard Rules is to ensure that girls, boys, women and men with disabilities have the same rights and obligations as citizens as other members of society.

The Swedish Disability Federation recommends that the Swedish State:

- Work to ensure that the gender perspective permeates studies, planning, the implementation, evaluation and revision of all social initiatives at all levels of society and in research.
- Initiate a study that thoroughly investigates and documents to what extent women and girls with disabilities are discriminated against compared with men and boys with disabilities. This appraisal should be performed in all areas covered by this Convention. The findings of the study should then form the basis for guaranteeing the Convention's rights.

Article 6

1 Work and employment

Statistics Sweden, SCB, has investigated the situation of people with disabilities on the labour market¹⁷. The study's findings included the following:

One in every five people stated that they have a disability. Since 1998, the proportion of those employed in this group of people with disabilities has declined from 65 to 62 per cent. This can be compared with 77 per cent of those without any kind of disability. The term 'employment' should be understood to mean work or participation in labour market measures. 6.3 per cent were openly unemployed (versus 5.1 per cent of the general population). Of those with mental disability, only 46 per cent are gainfully employed and 25 per cent have taken early retirement¹⁸. Handu's standard of living study¹⁹ from 2005 shows that only 36 per cent of people with mobility impairments are in gainful employment.

Only 10 per cent of women with acquired mobility impairments work on the open labour market.²⁰

Regardless of disability, the proportion of those gainfully employed is lowest in the group of people receiving assistance compensation: around 7 per cent were gainfully employed in 2002.^{21 22}

The statistics produced show that there is a sharp difference between the proportion of employed men and women with disabilities.²³ The proportion of those in full-time work (over 35 hours) was 82 per cent for men and 57 per cent for women. The proportion of those in long part-time work (20 – 34 hours) was 12 per cent for men and 34 per cent for women. The proportion of men working in short part-time work was 5 per cent for men and 7 per cent for women.

¹⁷ The situation of people with disabilities on the labour market 2004, SCB 2005

¹⁸ Living conditions, report 97, People with disabilities, SCB 2005

¹⁹ Standard of living study 2005, A report on the standard of living of people with mobility impairments, hard of hearing people, deaf people and people with visual impairments. The research establishment HANDU AB,

²⁰ The Swedish National Social Insurance Board, RFV analyses 2003:15

²¹ The situation of the people with disabilities on the labour market 2004, SCB 2005

²² National Board of Health and Welfare description of the situation of disability care, 2006

²³ SCB 2005, page 38

The Swedish Government has set out a clear target of 80 per cent employment for the entire population, including for people with reduced work capacity. In the light of the low level of employment among people with disabilities, a readjustment of policy priorities is needed.

The Swedish Disability Federation considers that:

- The Swedish Government must guarantee opportunities for work, employment and care under equal conditions for people with disabilities, regardless of gender and ethnicity.

2 Unemployed young people

Young people with congenital or early acquired disabilities are an especially vulnerable group. As described in article 13, pupils with disabilities experience great difficulties in completing their studies. Levels of education therefore play a major part in determining opportunities for securing work.

“The expert group for studies in public economics” (ESO) has investigated how things have gone for young people who have finished compulsory education with poor or incomplete qualifications or who have dropped out of secondary school.²⁴ ESO found that those who experienced school problems in compulsory education ended up in gainful employment to a much lesser extent than other people of equivalent age.

In the study’s discussions with employment agencies, many employment agencies criticised the schools for a lack of willingness to collaborate with the employment agencies when pupils make the transition from school to work. Experimental work to increase collaboration between schools and employment agencies has been carried out and has yielded good results²⁵. The final report also stresses that specific resources are needed for young people with disabilities.

The Swedish Disability Federation considers that:

- The Swedish Government must ensure the possibilities for people with disabilities to employment, occupation and earning of living on equal terms and independent of gender and ethnicity.

3 Negative attitudes and treatment – primary reasons for exclusion

Many people with disabilities find themselves outside the world of work. This is often due to negative attitudes. In 2004, Temo conducted an interview-based survey in

²⁴ Departmental series 2003:33, School failure – how did it go recently?

²⁵ Work and disabled young people – Final report from a 4-year trial, Series V 11 1

which 3 380 people aged upwards of 16 years old were asked various questions. On the question of whether their workplace had an open attitude to people with disabilities, the responses included the following:

- more than half answered that they did not know,
- 63 per cent responded in the affirmative,
- 70 per cent of those working in local government, for the county council or for central government responded in the affirmative,
- only 53 per cent of the self-employed responded in the affirmative,
- over 70 per cent of healthcare and medical treatment consultants responded in the affirmative.

The results show that a large element of the labour market does not regard people with disabilities as a natural part of the labour force.

The study (IFAU no. 2001:5) conducted to clarify to what extent employers will take on people with disabilities also provides an idea of awareness of various kinds of support. Most employers state that they have little knowledge of what support is available and which authorities are responsible for the support. Employers who had taken on people with disabilities had made use of various State support, chiefly wage contributions, but had also to a large extent provided scope for aptitude testing and practical work for people with disabilities seeking work. The employers rated this support highly. The study also showed that most of the employers who had taken on a person with disabilities had a more positive experience than they had expected. This indicates that employers often underestimate the person's work capacity.

Despite our long-standing work in Sweden in asserting the equal value of all people, many prejudices clearly prevail concerning people with disabilities. These prejudices affect our support system, public administration and also the individual. The negative expectations aroused by people with disabilities are also evinced by individuals, including those in authority, employers, work colleagues or the actual person with disabilities. If we do not remedy the creation of negative attitudes, it will be difficult for other initiatives to make any headway.

The "Pay contribution study" stresses a constructive proposal designed to improve the creation of attitudes, namely that people with reduced working capacity should be allowed to secure work placements with public sector employers.

The Swedish Disability Federation considers that:

- Creative and positive measures are needed with a view to eliminating negative attitudes and prejudices against people with disabilities. These are essential if policy reforms and labour market policy initiatives are to have the intended effect.
- It is of the utmost importance that labour market participants gain an understanding of what various disabilities can entail in different work situations.

- Labour market participants must receive information on the support that exists for easing the hiring of people with disabilities.
- The Swedish Disability Federation supports the Pay contribution study's proposal concerning special drives, including the proposal to give people with disabilities work placements with public sector employers.
- The State must review its public service agreement with the Sveriges Television to ensure a representation of people with disabilities that does not reinforce stereotypes that make it more difficult for people with disabilities to obtain work. Models for varied organised work in public service media exists in the international arena.
- Initiatives in public education must be carried out concerning the conditions under which people with disabilities can secure work, in a similar way to how efforts have been made to raise awareness of equality and ethnicity.

4 Guidance and employment service

Guidance

It is important that careers guidance is always based on the individual's desires, interest and opportunities. This is unfortunately often not the case for people with disabilities, for whom the guidance instead focuses on the individual's limitations. This anomaly can only be eliminated by knowledge and awareness of various disabilities being raised among individual counsellors and among those responsible for the various activities. Particularly for young people, it is important that they do not face attitudes that limit their own self image. When people of working age get a disability, there is also a need for more extensive guidance. On the path from sick-listing to, for example, retraining or various aptitude testing initiatives, many need a guide who can provide guidance between and through various social bodies.

Employment service

The task of the employment service is to prioritise those who find it difficult to secure work and those who have been out of work for a long while. These include job seekers with disabilities. This means that job seekers with disabilities are prioritised as participants in labour market policy programmes. Over the period 2001-2004, the proportion of participants with disabilities accounted on average for around 20 per cent of all participants.²⁶

Fewer job seekers with disabilities than others secure work through the employment service. Over the last 10 years, on average 22 per cent of male job seekers with

²⁶ Analysis of processes within the labour market policy sector that affect scope for achieving the disability policy targets, Reporting back: Disability policy according to the official document placing appropriations at the disposal of the authorities concerned 2005, the Swedish National Labour Market Board, page 22

occupational disabilities have secured work and around 20 per cent of women (annual average). For job seekers without an occupational disability, the corresponding measures are around 36 and 37 per cent respectively. The differences between people with and without disabilities become even more marked if subsidised jobs are disregarded. Without subsidy, about 10 per cent of men and about 12 per cent of women secured work.²⁷

The Swedish Disability Federation considers that:

- A comprehensive programme for raising competence among student counsellors and employment agencies should be implemented. The programme should first of all be aimed at raising awareness of the conditions for people with disabilities rather than knowledge of various diagnoses.

5 Labour market policy measures

In Sweden, there are many labour market policy measures that specifically concern people with disabilities. One of the most important is the job retraining programme. The efforts are intended to help achieve the target in the EU's employment guidelines. In other words, 25 per cent of the long-term unemployed should by 2010 participate in an active scheme consisting of training, retraining, practical work or other measures that promote employability.

The efforts via the labour market policy programme make it easier for job seekers with disabilities to secure work. A third of those who took part in various programme had work 90 days after the programme had come to an end, compared with around 40 per cent of applicants without disabilities.

It has emerged that men with disabilities are the object of activity-enhancing labour market measures while women with disabilities remain passive as a result of sickness and activity compensation²⁸

Pay contributions

Even when economic conditions are favourable, people with disabilities have found it difficult to enter the labour market. This situation has been addressed by various kinds of targeted support for enterprises with the aim that people with disabilities should be employable. The most extensive scheme of this kind is employment with pay contributions. Employers who appoint staff with reduced working capacity can be compensated economically with pay contributions. The size of the contribution is influenced by two factors: the wage cost for the employee and also the employee's working capacity in relation to the tasks of work.

²⁷ Ibid, page 23

²⁸ Report on the situation of disability care 2005, page 8, the National Board of Health and Welfare

When the pay contribution was introduced, the contribution-basing amount was at the same level as the regular wage level. The contribution-basing wage level has since remained steady for several decades. In spring 2005, it was decided that a smallish increase should take place. At the present time, the contribution-basing amount cannot in many cases be compared with current wage levels.

The Swedish Disability Federation fears that a form of contribution like the pay contribution will have an entirely different effect if it does not track the general pay trend. Not only does the employee risk standing still in terms of pay growth but also the employer's, the employment service's and the individual employee's view of the work contribution will be affected. The Swedish Disability Federation fears that an underfunded effort will reinforce prevailing prejudices.

In August 2005, around 87 500 people with disabilities had a job with a pay subsidy. This applies to employment with pay contributions (around 60 000 people), in public protected work and employment in protected work with Samhall AB. This is equivalent to around 28 per cent of the number of people with disabilities who have reduced working capacity and who are employed on the Swedish labour market.²⁹ The changes from the systems to the regular labour market are vanishingly few.

Samhall

Samhall AB is a State enterprise with the function of securing jobs for people with disability under market conditions. Samhall's task is to produce goods and services and thereby create meaningful and developing work for people with occupational disabilities. Samhall is also required each year to help 5 per cent of partners secure work outside Samhall. Samhall operates in more than 250 local authorities around Sweden. Just over 24 000 people work within Samhall and more than 90 per cent of these have an occupational disability. Samhall offers jobs to job seekers with one or more disabilities. The disability must result in reduced work capacity and difficulties in securing or retaining a job on the rest of the labour market.

The Swedish Disability Federation considers that:

- The labour market policy programmes for people with reduced working capacity must be reformed. Current programmes are, in relation to the scale of the costs, ineffective. Labour market policy initiatives for people with disabilities sustain an antiquated view, capture too small a proportion of the target group and lead to an altogether inadequate extent to unsubsidised jobs.
- The various forms of support must show closer co-ordination, a clearer effort to bolster the individual's competitiveness and to a much greater extent lead to work on the regular labour market. This change must also be capable of taking place without jeopardising the individual's security and scope for subsistence. Women and men with disabilities must be given equal opportunities for support initiatives.

²⁹ Analysis of processes within the labour market policy sector that affects opportunities for achieving disability policy targets, Reporting back: Disability policy according to the official document placing appropriations at the disposal of the authorities concerned for 2005, the Swedish National Labour Market Board

- The measures proposed in the Swedish Government's budget proposals for 2005 are too limited for the intentions of the investigations to be achieved.
- The pay contribution ceiling must be raised to a level corresponding to the general pay increase since the contribution was introduced, and then continuously adjusted to track the continued trend in pay.
- Samhall has an important function, but the great contribution in jobs for people with occupational disabilities must take place on the open labour market. A major aim of Samhall's activities is to prepare people with occupational disabilities for work on the regular labour market. The Swedish Disability Federation considers that these transitions have taken place to an inadequate extent.
- Samhall's monopoly must be abolished. Conditions must be created for other players to assume, under equal conditions, the task of work rehabilitation for people with reduced working capacity.

6 The social insurance office's initiatives and occupational rehabilitation

Many people with disabilities can testify to a "career" that evolves from studies via unemployment and various labour market policy initiatives before resulting in sickness or activity compensation (previously pre-retirement benefits).

The Swedish National Social Insurance Board has investigated the situation for people with disabilities who receive support from the social insurance office, for example disability allowance or assistance allowance.³⁰ The investigation shows that only just over a fifth of people covered by the study (22 per cent) worked on the open labour market. Over half (57 per cent) worked either on the open labour market or had some other form of employment. Of these, most had full pre-retirement benefits. The Swedish Disability Federation fears that a large proportion of those now with the social insurance office should instead be the object of labour market-oriented measures. The Swedish Disability Federation's experience is that any further step away from the labour market is a backward move in terms of the individual's opportunities for being able to provide for himself or herself.

Various bodies are responsible for the individual receiving the necessary habilitation, rehabilitation and occupational rehabilitation, depending on what situation the individual is in. The Swedish Disability Federation considers this to be a major problem in itself as individuals often end up between the various players' areas of responsibility.

³⁰ The National Social Insurance Board 2003. Inequality in living conditions – a comparison between people with disabilities and the rest of the population.

For example, the Working Environment Act requires the employer to ensure that there are organised adaptation and rehabilitation activities for those employed. Nevertheless, 15 per cent of those employed who were covered by SCB's study stated that they had not received the rehabilitation they needed to cope with the work. This applies to a larger proportion of women than men.

An overall assessment of the study of work-oriented rehabilitation³¹ shows that many individuals do not have their needs for help and support met by current schemes. The study also shows that active composite rehabilitation initiatives yield positive effects for the individual compared with passivity. The effects can be seen in the individual's performance, days taken off sick and entry or re-entry into working life. In addition, the study has found that the socioeconomic effects of composite rehabilitation are considerable relative to the probable cost for the actual rehabilitation. One krona provides a return of nine.

Sweden has ratified the International Labour Organisation's Convention No. 159 concerning Vocational Rehabilitation. For further information, see the Swedish Government's report to the International Labour Organisation: report for the period 1st July 1999 to 30th June 2004.

The Swedish Disability Federation considers that:

- It is a socioeconomic failure that one tenth of the labour force depends for its maintenance on sickness contributions. The Swedish Disability Federation supports the proposals of the Samhall and Pay Contribution Study concerning a more effective system for matching appropriate initiatives to the individual's needs. The initiatives must be based on a proper investigation of the individual's needs.
- The initiatives must to a greater extent be active and activating, as compared with the passive and passivating nature of current initiatives. The incentive for both the individual and the authority in charge must be clearly focussed on work and rehabilitation.
- Everyone gains from high-quality rehabilitation being initiated at an early stage. However, it is not only occupational or work-oriented rehabilitation that is important. As sicklisting must take place on medical grounds, the Swedish Disability Federation would stress that medical rehabilitation must come first, before work-oriented rehabilitation can be started.
- Women and men with disabilities must have equal opportunities for rehabilitation initiatives.
- There must be a public co-ordinator for habilitation, rehabilitation and occupational rehabilitation.

³¹ Study of work-oriented rehabilitation (S 1999:08), SOU 2000:78 August 2000, the Swedish Ministry of Health and Social Affairs

7 Employers' co-financing responsibility

As from 1 January 2005, employers have borne co-financing responsibility for 15 per cent of the cost of sickness benefit for employees. The intention of this is for employers to be encouraged to make active efforts to reduce absence due to illness.

The Swedish Disability Federation fears that the new sickness benefit responsibility for employers will mean the employer forsaking employees considered to be at risk of ill health. This may then lead to greater exclusion from the labour market, resulting in a further increase in ill health. It has already become apparent that more and more employers request health checkups for new employees (noted, for example, in the publication *Kommunaktuellt*).

The Swedish Disability Federation considers that:

- Responsibility for creating "work for all" does not only rest with employers but is also to a large extent a responsibility for both authorities and federations of trade unions.
- Instead of "shifting" increased cost liability on to employers, more active, early rehabilitation initiatives are needed above all.

8 The State as employer

The Standard Rules emphasise that, in their capacity as employers, States should create favourable conditions for the employment of persons with disabilities in the public sector. The national action plan for disability policy points out that the State has a specific responsibility in setting an example. Nonetheless, SCB's study shows that people with disabilities work for the State to a lesser extent than the population as a whole. Out of employed people with disabilities, only 4.6 per cent work for the State as compared with 5.9 per cent of the population as a whole. Only 3 per cent of those with reduced working capacity who are in employment work for the State.

A study commissioned by the Swedish Disability Ombudsman in 2003 shows that just over two thirds of State authorities conducted recruitment drives so that people with disabilities were not excluded. This concerns, among other things, how advertisements are formulated, how the application process is handled and how interviews are held. Not even one half of authorities stated that they had considered support and adaptation measures.

The Swedish Disability Federation considers that:

- The State administration should seize on the disability policy target of diversity also in the employer's role. This means, for example, reviewing recruitment routines.

9 Conclusions and recommendations

Ten years ago, a unanimous General Assembly adopted The Rules on the Equalization of Opportunities for Persons with Disabilities. These 22 Standard Rules guarantee full participation and equality for people with disabilities. The Standard Rules emphasise that "States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment."

Despite extensive legislation in this area in Sweden, many people with disabilities are excluded from work. The information in this section clearly shows that it is common to experience discrimination and that many do not receive the support they need. The low level of employment for people with disabilities is extremely serious! Readjustments of policy priorities are needed. Conditions must be created for making the most of people's resources and taking care of every individual's potential. Substantial resources must be deployed in schemes that lead to work. The great contribution of jobs for people with the occupational disabilities must take place on the open labour market.

The starting point for the recommendations below is General comment no. 5, points 21 and 22 and UN Standard Rule 7.

The Swedish Disability Federation recommends that the Swedish State:

- Work to ensure that young people with disabilities secure work by drawing up specific proposals for measures that lead to work.
- Fight negative attitudes to employees with disabilities among labour market participants, within the legal system and in the rest of society by implementing information initiatives that may increase awareness of the support initiatives that society can offer employers who appoint people with disabilities.
- Initiate an extensive programme to raise the competence of employment agencies in relation to disabilities.
- Instruct the State administration to seize on the disability policy target concerning diversity also in its role as an employer.
- Ensure that conditions are created which mean that people with disabilities can secure placements, within both the public and private sectors.
- Work to start up a functioning chain of activities that lead to work for women and men with disabilities by immediately translating the effective proposals in the Samhall study and in the "Individual in the centre" study into a government bill.
- Raise the pay contribution ceiling to a level that corresponds to the general increase in pay since the contribution was introduced. The contribution must then be continuously revised upwards so that it tracks the trend in pay.
- Abolish Samhall's monopoly and instead implement the model proposed in the "Not only Samhall" study.

Article 7

1 Equal pay for equal work

Equal pay for equal work is a principle that has long existed in Sweden, but for many people it is still not a reality. Only three groups of people with disabilities have pay that is as high as the average for full-time employees. These three groups are people with: heart disease, diabetes and psoriasis.³² Among other groups of people with disabilities, average work income is much lower. Particularly vulnerable groups are people with severe mobility impairments and people with visual impairment. Nor do those with stomach and bowel diseases or mental disabilities come close to the average work income level. The pay contribution report also shows that the low ceiling for the pay contribution-basing amount keeps down pay levels for employees with disabilities and that most employers adapt pay in accordance with this ceiling.³³ This contributes further to people with disabilities not always receiving equal pay for equal work.

The Swedish Disability Federation considers that:

- People with disabilities should have contractual pay. The principle of equal pay for equal work should apply regardless of the size of the pay contribution and independently of gender.

2 Adapted work conditions

The most serious deficiency in working life for people with disabilities is the working environment. Despite far-reaching working environment legislation, many do not receive the support they need in the workplace. Tens of thousand of people with disabilities cannot work under safe and healthy working conditions. They are not given a specially tailored work rate, local adaptation, adapted work tasks or other support that they need.

The Swedish Working Environment Act specifies that working conditions must be adapted to people's differing requirements in physical and mental terms. SCB's manpower study dating from 2005 shows, however, that scope for receiving support or adaptation depends on what one needs. One has the greatest chance if one needs adapted working hours or adapted assistive devices. Just over three quarters of those needing adapted working hours or assistive devices receive this, but only half of those needing special local adaptation (such as adapted toilets). Just over 60 per cent of those needing adapted work tasks and specially tailored work rates have their needs met. Fewer women than men receive the support they need. Scope for receiving special local adaptation has increased since 2002, but about one in three still state that they are not given access to this.

³² The pay contribution study, Government official reports, Arbetskraft, 2003:95

³³ The pay contribution study, Government official reports, Arbetskraft, 2003:95, p. 182

Need for adaptation among the non- employed

In the Swedish National Labour Market Board's analysis of the outside world dating from 2005, non-employed individuals with reduced work capacity were asked whether they would be able to engage in gainful employment if they had one of seven listed needs met. The needs listed were the same as those dealt with in the section above. Those questioned answered that on average they needed 1.5 measures to be able to work. The difference between women and men was very small. This meant that most of the non-employed consider that they would be able to work if only one adaptation measure was taken. The commonest assessment of need was adapted work tasks (40 per cent). Three out of ten stated they needed adapted working hours and/or a specially tailored work rate, and this applied both to men and to women. Compared with 2002, no major changes have taken place.³⁴

The Swedish Working Environment Act specifies that the workplace must be adapted to people's differing requirements. If the Act is not followed, the individual employee has little chance, however, of having his or her requirements met. Nor can the individual have his or her case reviewed in accordance with current discrimination legislation, except in special situations. The Act prohibiting discrimination in working life on grounds of disability does not contain any obligation to take supportive and adaptation measures during ongoing employment. The employer need only adopt such measures in connection with engagement, promotion and training for promotion. As long ago as the beginning of 2003, the Swedish Government explained that the question of supportive and adaptation measures during ongoing employment would be addressed during the year. However, the Swedish Government has still not submitted any proposals on this matter.

The Swedish Disability Federation considers that:

- Legislation governing the working environment in the workplace is deficient. Individual employees must be given a greater opportunity of receiving the adaptations they need.

3 Distribution of responsibility

The Working Environment Act and the General Insurance Act require the employer to adapt the individual's working conditions. The adaptation requirements are supported by scope for contributions from the social insurance office and the employment service. The social insurance offer is responsible for contributions for work assistive devices and arrangements at the workplace for employees. The employment service is responsible for corresponding contributions so that the unemployed can be given and perform work. The contribution may be made when someone is appointed and for needs arising in the first twelve months of employment.

³⁴ Analysis of processes within the labour market policy sector that affect scope for achieving the disability policy measures, Reporting back: Disability policy according to the official document placing appropriations at the disposal of the authorities for 2005, the Swedish National Labour Market Board

The Swedish Disability Federation considers that:

- The distribution of responsibilities between the social insurance office and the employment service must become clearer with regard to workplace adaptation.

4 Conclusions and recommendations

Many people with disabilities are excluded from work or cannot work in the regular labour market under safe and healthy working conditions. Only half of those who need special local adaptation of the premises receive this and only just over 60 per cent of those needing adapted work tasks and a specially tailored work rate have their needs met.

Individual employees must be given a greater opportunity of getting the workplace adaptation they need.

The starting point for the recommendations below is General comment no. 5 and UN Standard Rule 7.

The Swedish Disability Federation recommends the Swedish State to:

- Work to ensure that all employees can receive the adaptations they need by tightening up the current Working Environment Act, including in respect of raising competence in relation to disabilities.
- Raise the pay contribution ceiling to a level corresponding to the general increase in pay since the contribution was introduced. The contribution must then be continuously revised upwards so that it tracks the trend in pay.

Article 8 – formation of and affiliation to trade unions

The Swedish Disability Federation can verify that people with disabilities are not denied scope for setting up or joining trade unions.

Article 9

1 Introduction

In Sweden, there are many different forms of social insurance. Only the forms of social insurance to which the Swedish Disability Federation has paid special attention over the last year are dealt with below.

The Swedish Disability Federation is conscious of the security we have through the general social insurance system in Sweden. The deficiencies described below are relatively detailed but important to remedy if social insurance arrangements are to give the necessary social and economic security.

2 Sickness benefit

Anyone who has attained 16 years of age but who is not yet 65 and who, owing to illness, disability or some other reason, has his or her working capacity reduced by at least one quarter is entitled to sickness benefit. Sickness benefit requires the applicant to have a so-called sickness-based income, i.e. to have or have had a job and at the time be registered with the employment service.

Since 1998, the number of people on the sick list has risen, as has the costs of the sicklisting. More and more people are sicklisted for ever long periods of time. The proportion of all sicklisted people accounted for by women has risen almost continuously since the early 1990s, standing at nearly 64 per cent in December 2004.³⁵

Handling of matters

The Swedish Disability Federation's experience of sickness benefit is that certain groups, particularly those with invisible disabilities such as dental care injuries, electrocensitivity, whiplash, fibromyalgia and stomach and bowel diseases often meet with mistrust despite having medical certificates.

Insurance doctors are hired consultants who are required to help the Social Insurance Office's officials make medical assessments of other doctors' certificates. Their opinions are to be viewed only as advice, not as binding instructions. In practice, however, insurance doctors have considerable power and it is rare for a social insurance office's committee to go against its own consultant. These insurance doctors reject many diagnoses made by chief physicians, specialists within various areas and other doctors. It is not uncommon for patients to have approached a number of different doctors or specialists but for the diagnosis still not to be

³⁵ Scale and financing of social insurance 2003–2006, the Social Insurance Office 2005, page 19

approved by the insurance doctor men. The consequence of this is that people who are ill are left without sickness benefit.

Follow-up

Sickness benefit should be paid when people are sick and cannot work. It is therefore important that work capacity is checked. It is also important that sickness benefit is not viewed as a static compensation, but that it is checked once in a while whether someone in receipt of sickness benefit can work to some extent. It is important that the check takes place in a respectful way. The Swedish Disability Federation's experience is unfortunately that the Social Insurance Office's guidance often has an undertone of suspicion and an element of checking-up on individual policy holders instead of promoting and helping find appropriate rehabilitation initiatives.

Systems uncoordinated

The Social Insurance Office's analysis of the outside world in terms of the disability policy targets from 2005 show that the social insurance system and the labour market system are not co-ordinated satisfactorily. A clear example of this is the definition of work capacity that is fundamental to both systems. In the social insurance system, an individual can be considered to have partial working capacity if he can work 25 per cent of full-time. However, the labour market system requires capacity to work at least 17 hours a week (around 40 per cent of full-time) for an individual to be considered to have working capacity.

If the Social Insurance Office considers that an individual has a working capacity of 25 per cent, the sickness benefit can fall by the same percentage, despite the individual not being considered by the labour market to have the necessary working capacity. The curtailment of the sickness benefit means that people fall between society's protection systems and end up in economic difficulty.

Another aspect that contributes to economic difficulties for people who have been sicklisted but who wait for the necessary care or rehabilitation is the time limit that exists for the sickness benefit. People who have been sicklisted and who, owing to deficiencies in society's care efforts, are forced on to sickness benefit find it difficult to manage financially. In cases where the care is not satisfactory or if the waiting time for, say, operations becomes too long, the individual should not be affected by further difficulties in the form of a poorer financial situation.

The Swedish Disability Federation considers that:

- The Social Insurance Office's insurance doctors must work in a different way so that people in need of and entitled to support within the social insurance system can secure the support they need. Insurance doctors must, among other things, contact treatment-providing doctors to a greater extent. The healthcare and medical treatment systems must also improve in terms of insurance medicine so that they can issue the certificates required by the Social Insurance Office.
- A change in the law should take place so that insurance doctors can be held accountable if they make inaccurate judgements.

- As the Social Insurance Office's resources are not unlimited, the priority monitoring area for the Social Insurance Offices' officials, in relation to sickness benefit, should be to discharge responsibility for rehabilitation and to maintain continuous contact with the long-term sicklisted.
- The social insurance system and the labour market must collaborate so that people with disabilities receive the necessary support and do not fall between society's protection systems.
- The social insurance system and labour market participants must unite around a common definition of the term 'working capacity'.
- In cases where people in receipt of sickness benefit have not secured the necessary care by the deadline for the transition of the sickness benefit to sickness compensation, the sickness benefit must be extended until the customer has received the necessary treatment.

3 Activity and sickness compensation

For those who do not have any sickness benefit-basing income or whose disabilities is expected to last for more than one year, there is scope for receiving sickness compensation. For those between 19 and 30 years of age, the sickness compensation is replaced by activity compensation. The number of people in receipt of sickness or activity compensation has been growing for a number of years. The number of people in receipt of sickness or activity compensation was 555 775 in March 2006. Of these, 331 440 were women and 234 335 men.

For those in receipt of sickness or activity compensation but who want to try to work again, there are opportunities to apply for inactive compensation for no more than 2 years. Despite the fact that training is as a rule placed on a par with work, for example in relation to assessing working capacity, inactive compensation cannot currently be obtained for studies.

The Swedish Disability Federation considers that:

- It should be possible to obtain inactive compensation for studies as well. The Swedish Disability Federation considers that it is just as important to be given an opportunity to study as to be allowed to try out a job.

4 Disability allowance

Disability allowance can be obtained by anyone whose functional capacity is reduced if the disability is expected to persist for a relatively long while, generally at least one year. Anyone who has attained the age of 16 and who has received a disability before the age of 65 is entitled to disability allowance. One is also required:

- by virtue of the disability, to need more time-consuming help from someone else in one's daily life,

- in order to be able to be gainfully employed or study, still to need help from someone else owing to the disability,
- to have substantial additional expenses on account of the disability.

The compensation is for 69, 53 or 36 per cent of the base amount, according to the scale of the need for help or the scale of the additional expenses.

In June 2005, the number of people in receipt of disability allowance was 61 221.³⁶ Between 1998 and 2004, the number of recipients grew. Around 57 000 people over 16 years of age were in receipt of disability allowance in 1999.³⁷ Of recipients of disability allowance in June 2005, the proportion of women was just over 54 per cent and the proportion of men was just under 46 per cent. The proportion of women is half a percentage point higher than in 1998. Research has shown that women with disabilities are discriminated against as compared with men with disabilities in terms of the social insurance office's handling of disability allowance. For example, women more frequently receive lower allowance than men, according to Antoinette Hetzler.³⁸

The Swedish Disability Federation has arranged for the collection of information on how the possibility of obtaining disability allowance functions in practice. The paragraphs below address some of the problems that exist.

4.1 Attitudes and treatment

The information shows that organisations of people with disabilities receive, virtually daily, calls from members questioning the Social Insurance Office's assessments. Many people also want help with appealing against decisions or with applying for disability allowance. Many have reported that they felt wronged by the Social Insurance Office's decision and that they felt that their medical certificate, need for support or additional expenses had been called into question.

What is approved by the social insurance offices varies sharply and the assessments often end up being dependent on the social insurance office or officials. The social insurance office's officials in charge of cases reduce the sums involved despite the fact that the members are actually very restrained.

An example is provided by someone who had a food allergy. This condition was confirmed by a number of medical certificates. The Social Insurance Office claimed that the person in question suffered from hypersensitivity, for which disability allowance is not available. When the Social Insurance Office realised that they would lose in court, they approved the allergy, but reduced all the additional costs so these ended up just below the lowest level.

³⁶ The Social Insurance Fund's register database 2005

³⁷ Folksam 2000 and the Social Insurance Book 2000, the Swedish National Social Insurance Board

³⁸ Antoinette Hetzler Social policy in reality – People with disabilities and the Social Insurance Office 1994, page 88

4.2 Several levels

As stated above, disability allowance is available at three different levels. Which level of disability allowance the individual receives depends on the level of the need for help or the scale of the additional expenses.

There is a high threshold to overcome to receive disability allowance. Those who have costs below what triggers disability allowance may nevertheless have very difficult financial circumstances. A study from 1992 proposed that a further, lower level of disability allowance should be added, but nothing has still happened. In addition, people with an extensive disability may have additional expenses that far exceed 69 per cent of the respective base amount. According to a study commissioned by Uppsala University on behalf of the Swedish Federation of People with Mobility Impairments (DHR) on disability allowance in 1995, individuals with extensive mobility impairments in both their arms and legs faced an additional cost of SEK 80,000 – 85,000 per annum. The study also showed that these people are forced to live at an economic level far below the average as the additional costs owing to the disability account for such a large part of their budgets. Several later studies, including the study relating to “additional costs for rheumatic disease³⁹”, show a similar situation. The latter report also shows that only 8 per cent of members of the Swedish Rheumatism Association receive disability compensation.

The Swedish Disability Federation considers that:

- A new minimum and a new maximum level are required for disability allowance. The amount at which this level should be set needs to be further investigated, but compensation for the actual additional costs must be granted in a completely different way from today.
- Those in charge of cases at the social insurance offices should have a better understanding of the situation and additional costs of various groups of people with disabilities. This applies particularly to groups with invisible disabilities.

5 The situation for elderly people with disabilities

According to the Swedish Federation of People with Mobility Impairments, elderly people who have had mobility impairments for most of their lives often face an extremely difficult situation. Reasons for the serious economic situation in which many live include the 65-year limits for vehicle support, the disability allowance and personal assistance arising from LSS/“The Assistance Act” (LASS). There is also a halving of the pension contribution if one has previously had a pre-retirement benefits and also all the additional costs associated with the disability. These additional costs do not disappear as a result of someone attaining 65 years of age. It often becomes difficult for the elderly – particularly women – with disabilities to maintain a

³⁹ Additional costs for rheumatic disease. A study by the HANDU research association on behalf of the the Swedish Rheumatism Association, 2001

reasonable standard of living when the forms of support cease so drastically. Even if reservation amounts and maximum rates now exist, unfortunately they rarely take account of all the adaptation and additional costs that the disability entails.

The Swedish Disability Federation considers that:

- The 65-year limits for the various forms of social insurance must be reviewed and it is the individual woman's/man's needs that should be crucial, not age.

6 Economic support for families

For families with children, both practical and economic support is available from Swedish society. The practical support for families with members with disabilities is dealt with in article 10.

Economic family policy in Sweden covers a number of benefits, including child benefits, childcare benefits, temporary childcare benefits, home care allowance, maintenance support and housing allowance. Together, they are intended to help reduce the economic differences between households with and without children.

6.1 Temporary childcare benefits

Childcare benefits are paid when a child is born or when a family adopts a child. Parents who have children with disabilities may on certain occasions also claim temporary childcare benefits to be able to be with their children. They may for example be paid so that the parents will be able to attend the habilitation service, a special school or the like. Support may also be granted so that, for example, parents can attend parental training relating to the child's disability. Parents of children covered by LSS can claim temporary childcare benefits in cases where the parents need to relinquish gainful employment as a result of the child being ill or contagious. The temporary childcare benefits can be claimed only before the child has reached the age of 23. The Swedish Disability Federation's experience is that many children covered by LSS stay on at home with their parents after they have reached the age of 23, resulting in considerable additional costs for the parents. There are many reasons why children continue living at home. One is that these children often become independent of their parents later than other children. Another common occurrence is that the children can often not move out of the parental home because they have not been given access to the necessary special housing or the necessary assistance from the local authorities. For further information, see article 11. To enable these parents to cope with the financial burden resulting from children staying on at home, they should be given financial compensation while the children continue living at home.

The Swedish Disability Federation considers that:

- Temporary childcare benefit functions well, but a combining compensation model should be created for families whose children need to stay on at home after they have reached the age of 23.

6.2 Care allowance

The parents of a child with disabilities who have additional costs owing to the child's disability, for example for medical trips, special diet, medical care or medication, or where the child, by virtue of his or her disability, needs special supervision or care for at least six months, may be entitled to a care allowance. Care allowances can be claimed by parents once the child is newborn up to the June of the year in which the child reaches the age of 19. The person with disabilities can then apply for disability allowance. In June 2005, the number of recipients of care allowance was 39 046.⁴⁰

One problem with the care allowance is that it can be difficult for parents of children with disabilities to study. If a parent receives a full care allowance and has other income besides the studies, for example summer holidays, the latter receives reduced study support. This is due to the fact that part of the care allowance is a taxable benefit and is classed as income when one is studying. The Government should consider whether the care allowance should really be used as the basis when calculating study support.

Care allowance can only be paid to one parent if the parents do not live together. This is a major problem if the child lives alternately with his or her parents. (The Social Insurance Office has submitted a proposal for a change in this to the Government).

The Swedish Disability Federation considers that:

- The care allowance should not be counted as income when calculating study support.
- The care allowance should be shared if the children live with the parents alternately.

7 Conclusions and recommendations

The facts presented in this chapter show that social insurance offices in Sweden still do not afford sufficient protection to people with disabilities and their families.

The Swedish Disability Federation realises the importance and scope of the Swedish social insurance system, which gives us social and economic security and new opportunities. We appreciate the current system but consider that it can be improved.

Facts show that many people have a difficult financial situation. The disability movement in Sweden is partially involved in the ongoing process of improving the social insurance system, but does not consider that the collaboration can be improved further.

⁴⁰ The Social Insurance Office's register data 2005

The starting point for the recommendations below is General comment no. 5, point 28 and UN Standard Rules 8 and 18.

The Swedish Disability Federation recommends the Swedish State to:

- In future develop collaboration with the disability movement on all issues concerning the country's social insurance system. The Government and other affected parties should see the disability movement as a resource whose skills are essential for Sweden to have a fully functioning social insurance system.
- Ensure that the social insurance system functions for girls, boys, women and men with disabilities by, among other things, reviewing:
 - the role and responsibility of the insurance doctors. A change in the law is needed so that insurance doctors can also be made responsible when the need for measure is misjudged,
 - scope for claiming extended sickness benefit in cases where there is a lack of social care and treatment resources,
 - scope for receiving inactive sickness or activity compensation during training,
 - the levels of the disability compensation.

Article 10

1 Support for families

1.1 Support under the law

Swedish law gives families in which one or more family members have a disability right to support initiatives from society. The support may apply both to parents who have disabilities and to parents who have children with disabilities.

"The Act relating to support and service for certain people with disabilities" (LSS) provides, among other things, entitlement to:

- *advice*, which should be expert support for families and other relatives,
- *relief service*, which may for example involve someone taking care of a child with a disability for a shorter while so that a load is taken off the family,
- *short-term stays* which mean that children and young people covered by the LSS can be allowed to live with a different family or in a specially serviced dwelling for a certain time,
- *personal assistants*.

The Social Services Act gives family members not covered by the LSS an entitlement to certain support. For example, the local authorities' social committees provide support and relief for those looking after close relations who are long-term sick or have a disability.

The Swedish Disability Federation considers that:

- The intentions of the laws are good. The support initiatives meet many of the needs that people with disabilities have in order to be able to take part in society under equal terms.

1.2 Deficiencies in the system

In reality, there are deficiencies in the system with regard to the handling, assessment and implementation of the support efforts – theory and practice do not match up.

Co-ordination

A major problem for families who need support from society is the lack of co-ordination. An appraisal conducted by Dampens hus in Skaraborg provides telling examples. The appraisal shows among other things that:

- 78 per cent feel that they have not received information on what support society can provide,
- in one in four families, one of the parents is sicklisted,
- 60 per cent answered that one parent had had to reduce their working hours as a result of the situation at home,

- 83 per cent stated that there was no social representative who co-ordinates the activities/initiatives that apply to the child,
- the lack of co-ordinators mean that all social contact must be handled by the family,
- establishing and maintaining social contacts concerning the child can be a full-time job,
- in cases where the family had a co-ordinator, fewer parents were sick-listed or had not had to reduce their working hours.

Certain children with disabilities need initiatives that are within the local authority's and county council's area of responsibility. The National Board of Health and Welfare has conducted an appraisal⁴¹ of the agreements that exist between Sweden's local authorities and county councils with regard to the co-ordination of these initiatives.

The appraisal shows that only 43 local authorities (out of 290) have such agreements with their county councils.

Handling of cases

Studies⁴² conducted by the National Board of Health and Welfare show that the handling and investigation often seem to be conducted against a solution known in advance, namely what the local authority can offer. Documentation is often lacking on how the initiative is to be conducted. It is also common for individuals to be pushed around between officials and many feel that the officials dealing with their cases do not listen to them.⁴³

In 2005, the National Board of Health and Welfare conducted an interview study⁴⁴ with parents of children with extensive disabilities to investigate their experiences of the social services. The study showed that many parents felt:

- that they were shown a lack of respect and sympathy and felt that they were being checked up on and called into question by officials,
- that the officials in charge of the case did not have sufficient competence with regard to children with disabilities,
- that the authorities tended to direct investigations and initiatives based on existing resources instead of looking at individual needs and the intentions of the legislation.

⁴¹ National appraisal of collaboration agreements relating to children and young people with disabilities, National Board of Health and Welfare, 2005

⁴² Situation reports relating to the social services, National Board of Health and Welfare, 2004

⁴³ Disability care, The National Board of Health and Welfare, Situation report 2004, page 7 *et seq.*

⁴⁴ Competent parents – dependent on the support of social services, Dialogue with parents of children with extensive disabilities concerning their experiences of social services – after ten years with LSS, the National Board of Health and Welfare 2005

The National Board of Health and Welfare states that the study shows that the treatment of parents undermines scope for complying with the intentions of the laws. The implementation of the rights that exist pursuant to the law then risks standing or falling by individual officials, or as one parent put it: "If you lose a good official, you also lose confidence in the law."

Visible and invisible functional impairments

It is apparent from the study entitled "Adults with disabilities"⁴⁵ that officials in charge of cases have different views of people with visible and invisible disabilities. For those who have visible disabilities, the handling of the cases focussed almost entirely on what they could *not* do. With regard to people with invisible disabilities, it was difficult to get the official to understand what they needed help with. Many felt that their needs for support and help were called into question.

The Swedish Disability Federation's view is that the handling of the case would be improved if everyone were given individual plans, regardless of whether initiatives are covered by "The Social Services Act" or LSS. This is currently only a right pursuant to LSS. Individual plans provide structure for initiatives and measures and in this way release time and energy for parents and children. (This is apparent from a project conducted by the National Board of Health and Welfare.)

Parental responsibility

The term "normal parental responsibility" is intended to be a standard for what needs are to be met by parents and what needs are to be met by social services.

Parents interviewed feel that the term is used as an argument for rejecting applications, or reducing the scale of support efforts. The National Board of Health and Welfare has conducted a review of LSS judgments that shows that the significance of "normal parental responsibility" is still the object of legal review.

A number of the federations of people with disabilities have received information from individuals concerning a lack of understanding from various people with whom the individuals come into contact during both pregnancy and parenthood. The Swedish Disability Federation therefore has grounds to fear that both a lack of understanding and negative attitudes are shared by mother care centres, childbirth staff and officials at the local authorities. Understanding of the potential and needs of people with functional impairments in the parental role must also increase so that all people with disabilities can be given the best possible conditions for becoming parents. It is also necessary for officials in charge of cases to take account of whether there are several children in the family as this often means that the family needs support.

The Swedish Disability Federation considers that:

- Local authorities and county councils must draw up specific agreements concerning collaboration so that efforts can be guaranteed and quality-assured in cases involving a number of responsible authorities.

⁴⁵ Adults with disabilities, University of Stockholm, 2003

- Social services personnel should have adequate basic training and knowledge of disabilities, skills relating to the development and needs of girls and boys and attitudes and treatment issues. The Sisus programme for attitudes and treatment issues can form the basis for this work.
- Information on scope for support initiatives should always be based on the intentions of the legislation, and not on existing local resources.
- The handling of cases must always be based on individual needs and be planned from a long-term perspective and be equivalent across the country.
- Girls, boys, women and men who need support initiatives must be able to have an individual plan drawn up. This applies regardless of the support granted pursuant to LSS or SoL.
- To ensure the quality of activities both for professionals and for users, the local authorities should develop collaboration with the user organisations.

1.3 Decisions not implemented

A recurrent problem for parents is the dilemma that arises when the local authority takes a positive decision concerning efforts but does not implement the decision.⁴⁶ A lack of resources is often cited as the reason. This is usually because it is difficult to achieve short-term stays, to recruit personal assistants, relief staff, contacts or companions. The consequences are in many cases that the parents themselves are forced to implement the decision, by recruiting from among friends and acquaintances, introducing and training personnel. The local authorities' efforts in these cases are confined to the formal employer responsibility.

The Swedish Disability Federation considers that:

- The local authorities' inability to execute supportive decisions to the greatest extent is at odds with the disability policy targets of full participation in society for all people. To enable people with disabilities to have a chance of equal treatment, the laws must be followed and the authorities must comply with the decisions of the courts.
- Decisions not implemented pursuant to SoL and LSS must be covered by the provisions relating to sanction charges.
- Guidelines are needed for both the handling time and a reasonable time for executing decisions.

⁴⁶ Situation report on individual and family care 2004, the National Board of Health and Welfare, 2005

2 Violence against children with disabilities

The Committee against child abuse has conducted a study based on 5 000 questionnaires and interviews with children, young people and parents. The report shows that children with long-lasting illnesses or disabilities are at a clearly much greater risk than others of being abused by parents and siblings. Boys with disabilities were more vulnerable to bullying and abuse than girls. For children who had DAMP, mental disabilities or obesity, the risk of being subjected to such treatment increased by 25 per cent. Sexual assault consisted of both physical and mental violence.⁴⁷

Susanne Erlandsdotter-Andersson addressed sexual abuse of children in her examination work⁴⁸. She found that children who have been exposed to abuse find it difficult to obtain justice and redress, particularly in relation to sexual abuse. Legal security for the adult accused is fundamental and if the child is not sufficiently credible, the abuse may end up not being provable. For many children with disabilities, it can be difficult to provide a clear, detailed description of what happened. This may apply, for example, to children with mental disabilities or speaking impairments problems. So long as the legal system cannot take sufficient account of different children's ability to testify to abuse, not all children can obtain the necessary protection from the legal system.

The Swedish Disability Federation considers that:

- The attitudes and treatment of children with disabilities should be improved. The entire hearing and legal process must be designed so that it meets children's needs. All parties who come into contact with children suspected of having suffered abuse must be aware of the children's abilities for communication. In order to be able more clearly to find evidence that abuse has taken place, various parties who come into contact with children must also have the necessary awareness of what consequences abuse can have for children with various disabilities.

3 Violence against adults with disabilities

3.1 Vulnerability to violence

The statistics show that violence against and abuse of women is common in Sweden. Two thirds of all Swedish women between the ages of 18 and 64 feel that they have been subjected to violence and/or been sexually abused by a man after reaching the age of 15⁴⁹. The number of unreported cases of abuse is also considered to be high.

⁴⁷ All about disability no. 2, 2001.

⁴⁸ Susanne Erlandsdotter-Andersson, Sexual abuse of children, Uppsala University, 2003

⁴⁹ Lundgren, Eva, Heimer, Gun, Westerstrand, Jenny, Kalliokoski, Anne-Marie, The struck lady, Men's violence against women in an equal Sweden – a range study, p. 10, 2001

For one year, the Swedish Disability Federation conducted the project "Make the invisible visible! A project relating to violence – disability – a gender perspective." The project assessed to what extent people with disabilities are subjected to violence. The study showed, among other things, that:

- more women (43 per cent) than men (32 per cent) had been subjected to abuse,
- among both men and women, mental abuse was commonest,
- among women, a number of types of abuse that went on for a relatively long while were commoner,
- among women, the perpetrators were usually people whom the women knew,
- among women, isolated or repeated abuse for a shorter time was commoner,
- among men, the perpetrators were usually staff or other people known to them,
- nearly half the women stated that the abuse took place in the home,
- a third of the men stated that the abuse took place in the home,
- 40 per cent of women and 33 per cent of men were under 18 years of age when the most serious abuse took place,
- 89 per cent of women stated that they suffered mental damage after the abuse, and a third also reported physical harm,
- 36 per cent of men stated that they suffered physical or mental damage.

It is apparent from Handu's standard of living study dating from 2005 that 9 per cent of deaf people and 3 per cent of people with mobility impairments over the previous 12 months had been subjected to violence that resulted in injuries requiring attention by a doctor, dentist or nurse. This can be compared with a figure of 0.9 per cent of Sweden's total population in the same age group stating that they had been subjected to violence requiring medical treatment.

3.2 Women with mental disabilities

Women with mental disabilities are a particularly vulnerable group. In 2005, the National Board of Health and Welfare published an appraisal showing that 63 per cent of women had been subjected to abuse after the age of 16. The corresponding figure for the last year was 31 per cent.⁵⁰

Research⁵¹ has also shown that women with mental illness and disabilities risk being subjected to crime on more occasions than others. In one Swedish self-assessment study, 67 per cent of the women questioned state that they had been subjected to abuse on more than one occasion. Another Swedish study⁵² has shown that more than half the instances of abuse reported took place in the women's homes.

⁵⁰ Violence against women with mental disability – Incidence, treatment and access to support, the National Board of Health and Welfare, 2005, p. 32

⁵¹ Bengtsson-Tops, scale study (2004) relating to violence against women who have contact with psychiatry.

⁵² Ibid, see also Violence against women with mental disability – Incidence, treatment and access to support, the National Board of Health and Welfare, 2005, p. 35

Studies conducted by the National Board of Health and Welfare⁵³ show that the women are often in a position of dependence with respect to the perpetrator, who may be her partner or her next of kin, her carer, personal assistant or someone else closely related. Not only does this increase the dependence on the perpetrator but it also means that, if the women is subjected to abuse, it can be difficult to report this for fear of compulsory care or, in cases where the abuse has been perpetrated by staff, it can be difficult for her to be believed.

Various studies have show that the consequences for these women can be an impaired self-image, anxiety and agitation, fear, relationship problems, post-traumatic stress disorder and self-destructive behaviour.

It also happens that post-traumatic stress disorder is not distinguished from the main mental disability and is therefore not treated appropriately.

The Swedish Disability Federation considers that:

- Personnel working in social services, care, habilitation and other bodies concerned should be given training in identifying and dealing with abuse of children and adults with disabilities.
- Special attention should be given to the situation of women as women with disabilities are more vulnerable to abuse than men. One should have routines and strategies within social services, care, habilitation and other bodies concerned for being able to identify and deal with cases of abuse of women.
- In cases where someone is dependent on help and it is the helper who is suspected, there should be a willingness to change helpers.

3.3 Lack of support initiatives after abuse

In Sweden, the local authorities' social services have specific responsibility for providing support for women who have been subjected to violence. This is set out in the Social Services Act. In a national follow-up in 2000, the National Board of Health and Welfare stated, however, that this specific responsibility did not to any great extent affect social service work, routines or training initiatives. Most local authorities relied on non-profit-making women's centres. Centres for women and men now exist in about half the country's local authorities⁵⁴: around 160 women's centres and up to 40 men's centres. The non-profit-making centres provide support, help and sheltered housing for women and girls who have been subjected to violence. In a survey conducted by Amnesty, more than 90 per cent of the local authorities that replied answered that they gave financial assistance to women's centres (Amnesty, 2004). In a relatively small number of places, there are now also municipally run crisis centres for women and children. There are also a few crisis centres for men.

⁵³ Violence against women with mental disability – Incidence, treatment and access to support, the National Board of Health and Welfare, 2005, p. 33

⁵⁴ Situation report in individual and family care 2004, the National Board of Health and Welfare, 2005

In 2003, the Swedish Disability Ombudsman conducted a survey designed to establish accessibility and preparedness for receiving women with disabilities at operations specifically focussed on providing support for the victims of crime. The services that replied had a total of 23 465 visitors per annum. During 2002, there were known to be 160 women with disabilities who approached the services. The number of women with disabilities who approached the services is therefore, in relative terms, very low compared with the situation of other women. The survey also inquired whether anyone in the service knew of women with disabilities who had needed to contact the service but did not seek help. One service in ten answered that they were aware of such cases.

Several reasons were adduced to explain why these women had not sought help, including the fact that the man looks after the woman, that there is a lack of support and help from those around, that there is a lack of information on what help is available and that the woman cannot enter the premises. This was due, for example, to the fact that women who are hard of hearing cannot contact the service owing to a lack of communication facilities, the fact that women with personal assistants cannot be offered protected housing and that premises and toilets cannot be used by women who use wheelchairs. Most interviewed as part of the Swedish Disability Federation's project "Make the invisible visible" had not sought help anywhere. Many stated that they did not know whom to approach. None had sought help from the women's centre or social services. The commonest support was given by relatives and/or friends.

The Swedish Disability Federation considers that:

- Municipal women's and men's centres should be made accessible. This applies to information on the centres, communication with the centres and the physical environment at the centres.
The local authorities should impose requirements on and provide financial support to non-profit-making centres so that they can also be accessible.
- There should be special alternatives to current centres, i.e. centres that can accept people with special needs, including intellectual disabilities, brain injuries, neuropsychiatric and mental disabilities.

3.4 Reporting of crime and the legal process

According to a study conducted by the National Board of Health and Welfare⁵⁵, there are only a very few cases of family violence that are reported as crimes. The victim was a person with disabilities in fewer than ten per cent of the known cases. The legal process makes demands of vulnerable individuals. A vulnerable woman must be able to express what she has experienced and understand the significance of the violations. There are several types of disabilities that make it difficult or impossible to meet this requirement. For example, if someone has problems with perception,

⁵⁵ Barbro Lewin, *Who cares, Crime victims with disabilities*, 2002, p. 103

remembering or communicating, this can create problems in contact with the police and legal system.

In the training radio programme "Life force", a psychologist with considerable experience of dealing with men and women with intellectual disabilities who had experienced sexual abuse was interviewed. The number of unreported cases for this type of crime was, according to the psychologist, high and "the legal system deals with this very poorly". Of the eighteen cases with which he worked, there was only one case that led to a conviction. Legal proceedings did not even take place in the other cases^{56 57}.

The Swedish Disability Federation considers that:

- The attitudes and treatment of people with disabilities must be improved in a legal context. Personnel concerned should find out to what extent people with disabilities need special support and/or adaptation before and during the legal process. Where necessary, it must be possible to obtain special support, accessible information and communication in connection with police questioning, investigations and legal proceedings.
- The police and legal system should, together with the disability movement, develop information and training opportunities for personnel concerned. The training events should focus on attitudes and treatment issues and the specific needs that people with disabilities may have and how these needs should in purely practical terms be addressed during the legal process.

4 Conclusions and recommendations

In 2001, the Committee on the Elimination of Discrimination Against Women (CEDAW) drew up the Swedish Government's report on the Convention on the Elimination of All Forms of Discrimination against Women. In its conclusions, CEDAW stated that:

353. The Committee urges the Government to collect more data on the nature and scope of violence against women, in particular within the family, and to continue its efforts to implement and strengthen current policies aimed at combating violence, with special attention given to women with disabilities and migrant and minority women.

Based on this statement, General comment no. 16 "The equal right of men and women to the enjoyment of all economic, social and cultural rights" and on The Standard Rules, the Swedish Disability Federation can state that individuals and also families with family members with disabilities are still not given the necessary support and protection.

⁵⁶ Similar information emerges from the final report from the National Council for Women's Peace

⁵⁷ UR, Life force, May 2003.

The Swedish Disability Federation recommends the Swedish State to:

- Formulate regulations that guarantee collaboration and substance for initiatives in which local authorities and county councils are at the same time the responsible authorities.
- Ensure that "the Social Services Act" and "the Act relating to support and service for certain people with disabilities" are observed by:
 - working to ensure that a comprehensive system with strong sanctions is developed for cases where decisions laid down are not followed,
 - working to ensure that national guidelines for reasonable processing times and reasonable times for implementation are drawn up.
- Ensure that violence against and abuse of children, young people and adults with disabilities can be identified and that the necessary support can be obtained. This issue should be specifically identified in national training events for staff groups in the care, school, police and legal systems.
- Ensure that social services, healthcare and medical treatment sectors formulate strategies and methods for supporting girls, boys, women and men with disabilities.

Article 11

1 Standard of living of people with disabilities

There are sharp differences in standard of living between people with disabilities and the population as a whole. Living conditions are not equal, and participation in society is lower for people with disabilities than for the population at large.⁵⁸

As described in articles 6 and 7, the unemployment rate is up to 50 per cent among people with reduced working capacity. Handu's standard of living study⁵⁹ from 2005 shows that in certain groups the unemployment rate is over 60 per cent. A large proportion of people with disabilities also have lower pay than the average for the population. Among gainfully employed parents, the lack of a working income means that the household's disposable income is lower than the average. In the case of, for example, those with mental disabilities, disposable income is SEK 96 000 versus SEK 120 000 for the average.

Handu's report concerning individuals with visual impairment, people who are hard of hearing and people with mobility impairment shows that:

- a majority of respondents have a gross income below SEK 13,333 per month,
- two thirds of those with a gross income below SEK 13,333 per month are women,
- one in six has a gross income below SEK 7,333 per month,
- one in six with visual impairment or mobility impairment state that they have experienced difficulties coping with the ongoing expenses of food, rent and bills over the last 12 months,
- nearly one in five with mobility impairment or who are deaf and one in ten of people who are hard of hearing or with visual impairment state that they cannot afford all the necessary treatments and assistive devices for their disabilities.⁶⁰

It is more frequently women than men who lack a relatively small cash reserve and who have had difficulties paying ongoing household expenses over the last 12 months.

In the SCB standard of living study, one in two people with mental disability state that they have difficulty coping with ongoing expenses. Among people with disabilities who are over 65 years old, many have a substantially lower income than the average for the elderly population.

⁵⁸ Inequality in a comparison of living conditions between people with disabilities and the rest of the population. The Swedish National Social Insurance Board analyses 2003:15, page 48

⁵⁹ Standard of living study 2005, A report on standards of living for people with mobility impairment, people who are hard of hearing, deaf people and people with visual impairment. Research institute HANDU AB.

⁶⁰ Ibid, page 9

A study⁶¹ from 2001 shows that among people over the age of 65 with mobility impairment, 75 per cent have experienced a deterioration in their financial situation over the last three years. Among these, the absolute majority is women. The reasons for the poorer financial situation are stated as being home help and subsidised transport expenses, medical trips, expenses of visits to the doctor, medical treatment, medicines and special diets. Other reasons are a reduced pension, the withdrawal or lowering of disability allowance, the withdrawal of vehicle support, and other additional costs associated with the disability.

The Swedish Disability Federation considers that:

- The standard of living for people with disabilities should be raised in line with other citizens. As things currently stand, people with disabilities, particularly women, generally have both a lower income and higher costs.
- First of all, people with disabilities should be seen as a resource within society and be given access to work (see also the recommendations of the Swedish Disability Federation in article 6).
- For those with a reduced working capacity or who are forced to remain outside the labour market, society must provide compensation. The compensation levels for social insurance must be such that it is possible to live a dignified life.

2 Food

Asthma, allergies and hypersensitivity are increasing in Sweden and are common. In terms of food allergy or hypersensitivity to foodstuffs, one study⁶² shows that between 15 and 20 per cent of the Swedish population feel that they have some kind of hypersensitivity to foodstuffs.

The most serious reactions can lead to allergy shock and, in the worst cases, death. For people to be able to avoid such problems, a number of initiatives and changes in the current food system are needed.

One group that has difficulties having their nutritional needs met is people with stomach and bowel diseases. Those who have dietary substitutes/supplements and also eat ordinary food face substantial additional costs as a result of their nutritional needs. According to the Swedish Association of People with Stomach and Bowel Diseases, many of the association's members have problems procuring the food they need owing to the high costs.

⁶¹ Having mobility impairment and being over 65 years of age – an extended survey of home help, finances and rehabilitation, the Swedish Federation of People with Mobility Impairments, 2001

⁶² Treacherous food – on hypersensitivity to food and drink, Lecturer Ulf Bengtsson, Gothenburg, and lecturer Nils E Eriksson, Halmstad, Astra Zeneca Sverige AB

The Swedish Disability Federation considers that:

- The recommendations in the proposed national action plan of the Swedish Asthma and Allergy Association must be implemented. It is listed here, among other things, that:
 - all foods should be accompanied by full lists of ingredients,
 - special diets should be placed on a par with treatment and medicines.

3 Housing

3.1 Housing and assistance

For people with disabilities who need support for living an independent life, there are various local authority initiatives. One can, for example, live in one's own apartment but with various levels of local authority housing support, including home help. If such housing is not manageable, there are special kinds of housing, for example group homes or serviced homes with personnel initiatives of varying levels.

The above-mentioned support initiatives can be obtained according to the "Social Services Act" (SoL) and the "Act relating to support and service for certain people with disabilities" (LSS) and also the "Act on Assistance Compensation" (LASS). In cases where people covered by LSS need personal assistance for more than 20 hours a week, the Social Insurance Office takes over responsibility for costs from the local authority for the additional hours. This is regulated in the Act (1993:389) on Assistance Compensation (LASS) and in the Ordinance (1993:1091) on Assistance Compensation.

3.2 Homelessness

The last appraisal of homelessness in Sweden was conducted in 2005. In the spring of 2005, around 17 800 people were reported as being homeless. This represents more than a doubling since the previous appraisal⁶³, which had been conducted in 1999. A contributory reason to this is, however, the fact that the definition of who should be regarded as homeless has been expanded somewhat since 1999. The appraisal from 2005 shows that:

- Three quarters of those who are homeless are men and one quarter are women; the vast majority of those who are homeless were born in Sweden.
- People born outside Sweden are overrepresented relative to their share of the population as a whole.
- 40 per cent of the cases reported had mental problems.
- The women were more frequently stated to have mental problems, while men more frequently have abuse problems.

⁶³ The homeless in Sweden in 1999 – Who are they and what help do they get? The National Board of Health and Welfare

The Government official report entitled "Countering homelessness – a coherent strategy for society"⁶⁴ shows that people with mental disabilities are overrepresented among people who have been evicted from their homes. This is an indication that the local authority's housing support activities have not been expanded or do not function satisfactorily and that the local authority does not take responsibility for people with disabilities.

The Swedish Association for the ElectroSensitive conducted a study of its members in the spring of 2005. The study shows that 36 per cent of the association's members abandoned their homes owing to electromagnetic radiation and because they could not secure financial support to arrange for electrical remedial work on their homes⁶⁵.

3.3 Institutions and special homes

In Sweden, someone is regarded as resident in an institution if he or she lives in an old people's home, sheltered accommodation with full board and lodging including a "home for care and housing", a hospital, a nursing home or within long-term care:

- in the age range of 25-64 years old, half a per cent of the population lives in an institution,
- among younger people dependent on help, the proportion is nearly 4 per cent,
- among the elderly, the proportion is up to 13 per cent,
- in most groups with disabilities, the proportion of those resident in institutions in the younger age range is very small,
- among the elderly, the proportion is even higher, for example 9 per cent of people with severe mobility impairments reside in institutions.

A group home comprises a number of common spaces. The number of people who share these spaces must be small, no more than four. Security cannot be achieved in large groups, and the individual must be seen. The Swedish Disability Federation has noted a growing trend for insidious institutionalisation. An extremely alarming aspect is the verdict of the Supreme Administrative Court which, contrary to the views of the Swedish National Association for Persons with Intellectual Disability (FUB), the National Board of Health and Welfare, in the preliminary work on the LSS granted "approval" for six people to live in a group home.

3.4 Adequate housing

In interviews in Statistics Sweden's standard of living study, it was noted whether it was possible to enter the dwelling without needing to use stairs. It emerges here that 66 per cent of younger people with severe mobility impairments and 70 per cent of people dependent on help lack this facility.

⁶⁴ Countering homelessness – a coherent strategy for society, SOU 2001:95, p. 130

⁶⁵ The National Board of Housing, Building and Planning instructions "The National Board of Housing, Building and Planning Handbook BAB". The following is stated under point 6.7.11: "Contributions are not made for electrical remedial work". Reference is made to a statement by the National Board of Health and Welfare dated 21 November 1991 (32-8200/91) and a report (ref. no. 32-9581/95) as well as a governmental decision of 19/11/1992, ref. no. 92/7724J.

In its investigation "Housing for people with mental disability", the National Board of Health and Welfare concluded that the local authorities do not in practice plan adequately for giving people with mental disability opportunities for finding adapted housing in the home local authority with adequate care initiatives. The report also shows that local authorities additionally do not take adequate active steps to rehabilitate people in dwellings so that they can secure more suitable and independent housing.

The organisations of people with mobility impairments' assistive devices project 2003 shows that women consider, to a greater extent than men, that they have not had their homes adequately adapted.⁶⁶

A number of groups of people with disabilities, including the organisation for kidney patients, criticise the lack of adequate housing for those who need space for, for example, dialysis equipment in their homes.

3.5 Statistics on people "dependent on help"

Statistics Sweden's standard of living study has investigated how many people "dependent on help" exist in Sweden. The group of people "dependent on help" are taken to include those who have stated that they need help from someone else in moving within or outside the home, or who do not manage to buy their own food or take care of washing and cleaning.

Based on this definition, the group consists of 165 000 people, or just over 2 per cent of the population between the ages of 16 and 84. Nearly 65 per cent of these are women. 30 per cent – or around 50 000 people – are under the age of 65.

The National Board of Welfare and Health description of the situation of disability care dating from 2005 shows that in 2004 around 53 000 people benefited from initiatives pursuant to LSS and around 21 000 benefited from initiatives pursuant to "the Social Services Act". (This concerns people aged 0–64 years old with a home help or special housing). In November 2004, around 12 600 people received assistance allowance pursuant to LASS.

It has not been clarified how many people feel that they do not receive the support they need. The National Board of Health and Welfare is currently developing methods to be able to investigate living conditions among people with disabilities. It is, however, not yet clear when the actual investigation will be completed. Figures from 2003 show that just over around 2 000 applications pursuant to the Social Services Act (SoL) and LSS were rejected despite the fact that a need for the assistance or the initiatives was considered to exist.

Investigations show that a major problem exists with regard to co-ordination and handling of cases that concern SoL and LSS. The problems have been described in article 10. The Swedish Disability Federation chooses to refer to the section "decisions not implemented" in article 10.

⁶⁶ The organisations of people with mobility impairments' assistive devices project 2003, page 157

3.6 Decisions not implemented

The National Board of Health and Welfare and the county administrative boards have, via a survey of all local authorities, appraised the number, as of 1 January 2002, of decisions and judgments not implemented and rejection decisions despite an assessed need pursuant to SoL and LSS. The results of the appraisal show, among other things, that as of 1 January 2002 there were 2 500 decisions that had not been implemented in accordance with SoL. This means a reduction of just over 15 per cent compared with the measurement carried out one year earlier. At that same juncture, the number of decisions that were not implemented pursuant to LSS was around 2 800, an increase of nearly 10 per cent compared with one year earlier.

Decisions pursuant to SoL

Decisions concerning special housing pursuant to SoL were the initiatives that were most frequently not implemented, accounting for up to 90 per cent of all SoL decisions not implemented.

In nearly half of cases, people had had to wait four months or more for a decision on special housing to be implemented. Seven per cent had waited between one and two years.

On 1 January 2002, there were a total of 61 judgments, distributed between 23 local authorities, that had not been implemented. Of these, all but one related to special housing. The previous year, there were in total 48 judgments that were not implemented.

Decisions pursuant to LSS

Decisions not implemented pursuant to LSS related chiefly to the contribution by the contact, though to a large extent also to decisions on the initiative for specially serviced housing.

Of those waiting for specially serviced housing, more than two thirds had been waiting for more than six months for the decision to be implemented.

The study shows that waiting times are longer for those who waited for implementation of decisions pursuant to LSS than pursuant to SoL.

There were judgments not implemented in 39 local authorities, and the number rose from 129 to 173 between 1 January 2001 and 1 January 2002. These judgments applied for the most part to specially serviced housing for adults.⁶⁷

Sanctions

Until 1 July 2002, a local authority that does not implement a judgment pursuant to Chapter 4 (1) of the SoL and section 9 of the LSS can be ordered to pay a sanction charge of between 10 000 and one million kronor.

⁶⁷ Decisions and judgments pursuant to SoL and LSS 2001 not implemented, 2003-109-6, the National Board of Health and Welfare, 2003

Lack of homes

In relation to the initiatives concerning housing for adults pursuant to LSS, housing for the elderly and to a certain extent short-term stays pursuant to LSS, the above-mentioned supervisory report from the National Board of Health and Welfare states that the reasons for the decisions not implemented are a lack of dwellings for these groups in the local authorities. A number of local authorities also have a lack of planning for being able to meet future housing needs. The Swedish Disability Federation, like the National Board of Health and Welfare, wishes to place the problem of the large number of decisions not implemented in a broader context than merely the lack of places in dwellings that provide care for the elderly and people with disabilities.

3.7 Lack of competent personnel

A major problem for people with disabilities is access to competent care personnel, including assistants. Four in every ten care workers lack any formal vocational training. In addition, terms of employment and working environments are not good enough to attract sufficient numbers of professionally competent individuals. Access to personnel with care training at upper secondary education level does not meet expected demand by a long way.⁶⁸

The Swedish Disability Federation considers that:

- The Act relating to support and service for certain people with disabilities and the intentions of the Social Services Act are good. There are, however, major deficiencies in the handling, assessment and implementation of support initiatives – theory and practice do not match up.
- Special support initiatives must be implemented for groups of people with disabilities who are homeless or at risk of becoming homeless. For example, people with electrosensitivity must be given financial support for electrical remedial work on their homes.
- Low-radiation areas need to be created as a temporary solution where emergency evacuation and rehabilitation of people with electrosensitivity takes place.
- The support initiatives devised pursuant to LSS must take account of the fact that women and men can have differing needs and desires in terms of types of housing, work and leisure.
- The local authorities' inability to implement favourable decisions conflicts to the greatest extent with the disability policy objectives of full participation in society for all people, regardless of disability. Support pursuant to SoL and LSS is often essential for people with disabilities to be able to participate in society and contribute to their own provision. The laws should be observed and the authorities should comply with the verdicts of the courts.

⁶⁸ INVEST NOW! Action plan for maintaining competence in care, 2004, <http://www.ky.se/rapportermm/pminvesternu.pdf>.

- Decisions not implemented pursuant to SoL and LSS need to be covered by the provisions of sanction charges.
- Guidelines need to be drawn up for both handling times and what is a reasonable time for implementing decisions.
- The national plan for coping with skills provision within the local authorities concerning care of the elderly and people with disabilities, Invest now, should be followed.
- Accessibility, the environment and servicing in local housing areas must be improved so that people with disabilities can continue living there. A better expanded home help/home medical treatment service and increased collaboration with healthcare and medical treatment concerning, among other things, rehabilitation initiatives can reduce the need for special housing and specially serviced dwellings.
- Alternative types of housing for people in need of special housing must be developed.
- The local authorities must follow existing legislation relating to building.

4 Assistive devices

An important requirement for people with disabilities in being able to cope in their everyday lives is assistive devices. In Sweden, people with disabilities usually obtain their assistive devices via healthcare and medical treatment or as assistive devices at work. Assistive devices are supplied to a large extent by county councils and local authorities pursuant to the "Healthcare and Medical Treatment Act" (HSL). Responsibility pursuant to HSL encompasses assistive devices for daily living, for care and treatment and also personal assistive devices for school and education. Work assistive devices for people with a reduced working capacity are the responsibility of social insurance offices and employment agencies.

The provisions and routines relating to the allocation of assistive devices are applied very differently across the country. In certain parts of Sweden, around SEK 7 000 must be paid for hearing aids for both ears and over SEK 1 000 a year for an electric wheelchair. In other parts of the country, the same assistive devices can be provided at little or no charge.⁶⁹ As described in section 1, people with disabilities are, in normal income situations, at risk of not having a cash reserve and not managing to pay ongoing expenses. Unreasonable costs for assistive devices can lead to people with disabilities being forced to dispense with the assistive devices they need to lead an independent life.

⁶⁹ Government official report, LSS and assistive devices report, SOU 2004:83

Handu has, in its standard of living study, investigated to what extent people with disabilities receive the assistive devices they need. The following points, for example, are particularly worthy of note:

- 26 per cent of people who are hard of hearing aged 16-64 years old state that they lack assistive devices for the workplace,
- 13 per cent of people who are hard of hearing state that they lack assistive devices for school and education,
- 15 per cent of deaf people who need assistive devices state that they lack hearing aids,
- people with visual impairment lack information aids. 13 per cent state that they need a magnifying device so that they can read written text. 16 per cent do not have access to a Daisy player and cannot therefore read spoken books,
- 3 per cent of respondents with visual impairment state that they do not have a white stick, although they need one.

With regard to the provision of assistive devices, see section 1.3 in article 13. There are a number of women who use assistive devices, but they pay for them themselves more frequently than men. There are more men than women who are given individually tested assistive devices.⁷⁰ Men and boys were granted more payments for vehicle support than women and girls in 2004.⁷¹ The organisations of people with mobility impairment's assistive devices project 2003 reports that men have their vehicles adapted to a greater extent than women.⁷²

The Assistive Devices Report (SOU 2004:83) has investigated how the provision of assistive devices should function in Sweden. The Swedish Disability Federation supports the proposals of the Assistive Devices Report concerning measures and calls on the Swedish Government to follow the report proposals though also to undertake further investigation of the provision of assistive devices.

The Swedish Disability Federation considers that:

- All individuals with disabilities should be given access to the assistive devices they need to enable everyday life to work. Users' opportunities for obtaining assistive devices should be dictated by their needs, not their personal financial situation. Anything else should conflict with the targets for the national disability policy or The Standard Rules on which the national action plan is based.
- Another investigation needs to be conducted that grapples more effectively with assistive device matters. The investigation may be designed to:

⁷⁰ SOU1998:138, Women, men and disability, page 17.

⁷¹ Ibid, page 24

⁷² The organisations of people with mobility impairment's assistive devices 2003, page 157

- formulate a definition of what an assistive device is,
 - propose how legal support for entitlement to assistive devices can be formulated,
 - draw up proposals for the co-ordination of the organisation responsible,
 - resolve matters concerning ownership and insurance.
- Children (and adults) should be given the right to assistive devices for play and leisure.
- Children should not pay charges for trying out assistive devices.

5 Conclusions and recommendations

The facts presented in this section show that people with disabilities do not have the same standard of living as, or a similar one to, people without disabilities. The laws governing assistance and housing are sound, but the handling of cases, co-ordination and implementation by the local authorities must be improved substantially so that girls, boys, women and men with disabilities can participate in society.

The starting point for the recommendations below is General comment no. 5 point 33, General comment no. 4 point 8 and UN Standard Rule 4.

The Swedish Disability Federation recommends the Swedish State to:

- Bolster the individual's opportunities for having his or her statutory right to assistance and housing met by introducing sanction provisions in the "Act relating to support and service for certain people with disabilities" and in the "Social Services Act" in cases where local authorities do not implement decisions already taken.
- Draw up guidelines for both handling time and a reasonable time for implementing decisions under the "Act relating to support and service for certain people with disabilities" and the "Social Services Act" so that the sanction provisions can be made uniform.
- Draft guidelines to enhance accessibility, the environment and servicing in local residential areas so that people with disabilities can continue living in their homes.
- Review and improve the provision of assistive devices nationwide.

Article 12

1 Standard of health

1.1 Introduction

In this article, the Swedish Disability Federation provides an account of how people with disabilities experience their health and also causes of ill-health among people with disabilities. Section 2 shows how healthcare and medical treatment function and what the Swedish Disability Federation considers should be done for healthcare and medical treatment to be more appropriate for people with disabilities. Section 3 deals with rehabilitation and habilitation.

We have chosen not to deal specifically with private care providers in this article. The Swedish Disability Federation would emphasise, however, that private care be subordinate to the same laws, rules and quality requirements as public care.

1.2 Statistics

The information in this chapter has been taken from the Statistics of Sweden standard of living study, report 97, 2003.

People with disabilities state to a greater extent than the general population that they have health problems. Depending on the nature and degree of the disability, the experience also varies sharply between the groups of people with disabilities. This phenomenon is commonest among people of working age with severe mobility impairment, with as high a proportion as 85 per cent stating that they have severe health problems. People with severe mobility impairment are also the most vulnerable in the 65-84 age group. Among those with stomach and bowel diseases and with mental disabilities, around one third feel that their health is poor.

People with disabilities state to a much greater extent than the general population that they have a number of long-lasting illnesses. The number of reported long-lasting illnesses is on average highest among elderly people with mobility impairment, elderly with visual impairment, and elderly people with mental disabilities. In the younger age group, people with severe motor disability have protracted illnesses most.

The National Board of Health and Welfare description of the situation dating from 2004 also shows that people with disability of different ethnic background, generally speaking, have poorer health. The difference is greatest between Swedes and people coming from countries outside Europe.

The groups who have great problems with health also present a higher consumption of care relative to the population at large. With regard to doctors' visits, however, the differences are small between the elderly and younger people with disabilities.

Regardless of age group, the proportion of women who feel that they have severe problems is higher than the proportion of men. Women also report side effects more frequently and are afflicted by medication-related ill health more frequently than men.⁷³

Many of those questioned who have disabilities do not feel, however, that their health is poor or poorer than people of the same age. There is no simple relationship between these indicators.

Trends in health

Electrosensitivity is becoming increasingly common in Sweden. Around 200,000 Swedes, or 3.1 per cent of Sweden's adult population, stated in a health survey that they are hypersensitive to electrical/magnetic fields.⁷⁴

Asthma, allergic diseases and hypersensitivity are still increasing in Sweden⁷⁵. In the SCB study of living conditions (ULF) based on the years 1999–2001, 20 per cent of the population aged 16–84 indicated that they have some form of allergic condition. At the same time as asthma and allergic conditions have increased, medical care has developed. The number of deaths from asthma has steadily declined since the early 1980s. The number of admissions to hospital has also fallen.

Over the last 20 years, the proportion of people who are hard of hearing has risen in all ages under 65. Clearly the greatest increase is observed in the 35–44 age range, in which just over 8 per cent have problems with hearing in conversations with others. This means that nearly a doubling has taken place in only 15 years. In addition, nearly 12 per cent of all people who are hard of hearing state that their general health is poor. This is more than twice the proportion for the population as a whole.

Causes of ill health

How people experience their health depends a great deal on how they experience their living situation. A high proportion of people with disabilities live in financially difficult circumstances. For example, one in two people with mental conditions find it difficult to cope with ongoing expenses. Nearly one in five people with mobility impairment or deaf people cannot afford all the necessary treatments and assistive devices.⁷⁶ See also article 11.

It is apparent from the annual report entitled "Truth and consequences" that one of the main reasons for ill health among people who are hard of hearing is that too few are given adequate hearing rehabilitation, despite the fact that county councils are obliged to offer rehabilitation pursuant to the Healthcare and Medical Treatment Act

⁷³ National Board of Health and Welfare report Equal care? From 2004

⁷⁴ Environmental health report 2001/Health survey 1999).

⁷⁵ Public health report 2005, National Board of Health and Welfare, p. 182 *et seq.*

⁷⁶ The National Board of Health and Welfare description of the situation of healthcare and medical treatment, 2004, page 9

(HSL, section 3b). Waiting times for hearing treatment are in many cases extremely long. Nearly one in three hearing centres have waiting times of one year or more.

One report⁷⁷ that was presented in spring 2006 shows that a reason for ill health is the experience of discrimination and abusive treatment. The report shows that:

- Reduced mental well-being is 3-4 times as common among people who have been subjected to abusive treatment.

- Suicidal thoughts and suicide attempts are 3-4 times as common among people who have been subjected to abusive treatment.

- Among those subjected to abusive treatment, it is 6 times commoner for men and 2-3 times commoner for women to experience stress or severe anxiety, agitation and anguish.

Another reason for ill health is deficiencies in healthcare and medical treatment. For more specific information, see the next chapter. We would, however, emphasise in this section that men and women are treated differently within the care arena. The committee on the treatment of healthcare and medical treatment (SOU 1996:133) found that women and men are treated differently. One of the reasons for this is that medical research and development are often based on men and their physical and social requirements. Women and men need not always have the same care to receive equivalent care, the committee found. Equal care can mean different care, but it should be based on awareness of the differing disease profiles and differing needs of women and men. With reference to the fact that women experience health problems to a much greater extent, it is extremely important that research, medical treatment, medication, etc. take account of both women and men.

In addition, the disability, or rather the diseases or damage from which it originates can, in certain cases, aggravate someone's general state of health.

2 Healthcare and medical treatment

2.1 Geographical changes

Access to care and care quality varies widely across the country. The population is being increasingly concentrated into the conurbations and a few growth areas, while many local authorities are seeing their population decline. These shifts mean that the population-related and economic basis for healthcare and medical treatment activities is being eroded. The shrinking finances of organisations responsible for medical treatment, increasingly sophisticated medical equipment, new medicines, computer-based aids, etc. in combination with the increased care needs of inhabitants therefore call for increased resources so that the needs can be met.

⁷⁷ Specially treated and abused – a report on the link between discrimination and health, the National Institute of Public Health in Sweden, 2006.

The Swedish Disability Federation considers that:

- Nobody should need to be given poorer care as a result of living in a local authority or county council area with high unemployment, sharp falls in population and an ageing population.
- In the absence of adequate skills in local medical treatment, the patient must be given a regulated opportunity for care outside his or her own county council area.
- The State, county councils and local authorities have joint responsibility for finding a solution to the consequences of regional policy changes on healthcare and medical treatment.

2.2 National guidelines

The National Board of Health and Welfare has the task of drawing up national guidelines for medical treatment. Through the national guidelines, the National Board of Health and Welfare defines what is to be regarded as good care.

The impact of the guidelines is inadequate in the various county council areas. Collaboration between the State, county councils and local authorities is not functioning satisfactorily. In addition, there are many groups of people with disabilities who have still not received national guidelines.

The Swedish Disability Federation considers that:

- It is very important that healthcare and medical treatment be assigned national guidelines for all diagnosis groups. This is in order to achieve higher quality for the care and also comparable care initiatives throughout the country.
- Existing national guidelines must be further developed.
- National guidelines must be drawn up, including with content that goes beyond the purely medical. For example, guidelines are needed for an effective care chain, for care and collaboration as well as for content and quality in habilitation and in acute and continuous rehabilitation.

2.3 Lack of compliance with laws and agreements

The Swedish National Audit Office has found that the guidelines for healthcare and medical treatment have not had the intended impact and are therefore not being implemented in practice⁷⁸. The Swedish Parliament's prioritisation decision means that those with the greatest need of healthcare and medical treatment must be given priority for care.

Many people with disabilities are among those who must be prioritised according to the Swedish Parliament's decision. Failure to follow the prioritisation decision may result in lifelong severe physical and mental health problems.

⁷⁸ The Swedish National Audit Office 2004

The Swedish Parliament's decision on prioritisation does not indicate any clear limits on the length of time for which responsibility extends for publicly funded healthcare and medical treatment. Nor does the decision provide any guidance on lower-priority needs or when the costs for a certain medical treatment initiative can be considered too high relative to the benefit for the patient.

The Swedish Disability Federation considers that:

- The prioritisation decision must serve as a guideline in all planning in healthcare and medical treatment and must apply to all initiatives – care and treatment, habilitation, rehabilitation, dental care and medicines.
- The Swedish Parliament's prioritisation decision must be supplemented by clear limits on the length of time for which responsibility extends for publicly funded healthcare and medical treatment. The decision must also be supplemented by guidance on lower-priority needs of when the costs of a certain medical treatment initiative can be considered too high relative to the benefit for the patient.
- The disability movement's skills must be used when the range of care is being planned and when quality and initiatives are being discussed. Our broad experience is an unexploited resource.
- The National Board of Health and Welfare, which is the authority that supervises healthcare and medical treatment, must reinforce its supervision so that those involved in healthcare and medical treatment comply with the regulations that exist.

2.4 Some particularly vulnerable groups

People with electrosensitivity, dental care injuries and mental disabilities are examples of groups who find it difficult to secure adequate care.

Just over 400 people have described in a letter to the Swedish Council for Working Life (RALF; now the Swedish Council for Working Life and Social Research, FAS) described what it is like to live with electrosensitivity in today's IT society. Many testify, for example, to a lack of knowledge within the care arena, poor treatment and a lack of beds specifically redesigned for people with electrosensitivity.

Many people with dental care injuries have experienced considerable difficulties in securing good treatment and effective care. The regulatory system places them in the legislative twilight zone between medical treatment and dental care, which has made the rehabilitation process more difficult. The Swedish Association of Dental Mercury Patients has studied all parliamentary and governmental decisions on dental care injuries since 1980. Not a single decision has been implemented as intended.

It is apparent from the National Board of Health and Welfare report on the situation of healthcare and medical treatment dating from 2004 that statutory care planning does not function satisfactorily for people with psychosis or with a combination of abuse and personality disorders. The people concerned have often received care of various kinds and considerable resources have been deployed without yielding first-class results. It is nevertheless probable that more co-ordinated and clearly evidence-based initiatives would yield better results.

The Swedish Disability Federation considers that:

- People with electrosensitivity must, like others, receive the necessary care so that they can attain the best possible health. Guidelines on what care should be available must be drawn up in collaboration with the Swedish Association for the ElectroSensitive.
- The lack of beds specially adapted to people with electrosensitivity must be remedied. Beds must be available within all county council areas.
- To enable people with dental care injuries or with electrosensitivity to secure the necessary care, training of all care personnel and for prospective doctors and dentists is required.⁷⁹
- A blanket ban on the use of mercury in dental material must be introduced. The ban must be accompanied by clear, simple, unambiguous regulations. The measures proposed in the dental report must be implemented as soon as possible.

2.5 Specialist care

The patient population can sometimes be so small that it is not possible to provide specialist resources within all county council areas. In addition, there is a lack of specialist doctors within certain areas. To meet the needs of certain target groups more effectively, for example for small and lesser known groups of people with disabilities, certain specialist care must be centralised so that it is possible to use competence and resources more effectively. Accessing resources outside the specific county council area or in other countries increases the prospects of being able to secure care under equal conditions.

The Swedish Disability Federation considers that:

- In order to meet the needs of certain target groups more effectively, for example for small and lesser known groups of people with disabilities, relevant specialist care must be centralised.

3 Habilitation and rehabilitation

In Sweden, the county council has prime responsibility for ensuring that inhabitants in the county council area are given rehabilitation. The local authority is, however, responsible for habilitation and rehabilitation in connection with certain initiatives pursuant to the Social Services Act.

⁷⁹ For further information on the training of care personnel, see the Swedish Association of Dental Mercury Patients.

With regard to certain initiatives from the county council, it is difficult to gain a comprehensive view of the scale and quality of the rehabilitation and habilitation activities. The county council's appraisals and reporting system do not cover habilitation and rehabilitation, and so these initiatives cannot be followed up in an acceptable manner in terms of either needs or resources.

Habilitation and rehabilitation for children and young people

Many children and young people with disabilities are given good habilitation and rehabilitation⁸⁰. The deficiencies uncovered by earlier studies remain, however. Access to habilitation and rehabilitation is unevenly distributed, between different parts of the country, between different groups of people with disabilities and also within one and the same county council area. The groups that usually have access to habilitation/rehabilitation are children and young people with intellectual disabilities, mobility impairment and neurological injuries and diseases.

The groups of children and young people who do not have their needs for habilitation/rehabilitation met are mainly those with disabilities as a result of ADHD, autism-like conditions and autism, though also children with multiple disabilities, medical disabilities and certain communication disabilities, e.g. visual impairment and speaking impairments. The study also shows that there are deficiencies in collaboration, both internally within the county councils and externally between the county councils' various activities and, for example, schools. Many clinics lack documented routines for collecting information and views from children/young people and their families. The study also shows that the county councils' appraisals do not report which children/young people need habilitation/rehabilitation, how many they are, how old they are or what kind of disabilities are involved and what the needs are. Nor can the county councils report what resources are deployed in habilitation/rehabilitation for children and young people, whether financial or in terms of personnel. The individual's scope for influencing his or her own habilitation/rehabilitation is limited. This seems particularly to be true of children whose parents were not born in Sweden, have low levels of education and/or low income levels.

Handu's standard of living study⁸¹ showed that around 60 per cent of children who are hard of hearing do not have a habilitation plan. In cases where such a plan existed, only half of the parents had taken part in drawing up the plans. A habilitation plan addressed the various initiatives that are relevant to the child. The fact that nearly two in three children who are hard of hearing do not have a plan of this kind is a shortcoming that has consequences for the quality of the habilitation.

⁸⁰ Access to habilitation and rehabilitation for children and young people with functional impediments – an appraisal' Stockholm' the National Board of Health and Welfare, 2003

⁸¹ Standard of living study 2005, A report on standards of living for people with mobility impairment, people who are hard of hearing, deaf people and visually impaired. . Research institute HANDU AB.

Rehabilitation for adults with disabilities

In an appraisal of access to habilitation and rehabilitation pursuant to the Healthcare and Medical Treatment Act for adults with disabilities dating from 2004⁸², the National Board of Health and Welfare states that, to a large extent, the county councils lacks activity plans/programmes for habilitation and rehabilitation. In the users' own view, there are also shortcomings in accessibility. This area therefore needs to develop so that the intentions of the Healthcare and Medical Treatment Act become reality. The appraisal shows that the individual habilitation/rehabilitation plans are an underused instrument for structuring the initiatives.

One group that needs to be highlighted is people with mental disabilities. Many examples of proper care and good habilitation and rehabilitation initiatives exist, but studies conducted⁸³ clearly show that very few are informed of the methods which, for all that, have proven to be successful.

According to Handu's standard of living study from 2005, only half the respondents state that they are satisfied with the rehabilitation/habilitation that they received over the past 5 years. In total, 17 per cent of members of the Swedish Federation of People with Mobility Impairments in need of rehabilitation or habilitation state, for example, that they have received very little or no rehabilitation over the previous 5 years.

Around one third, 28 per cent, of members with mobility impairment and one tenth of the other groups needing rehabilitation/habilitation state that they need an individual rehabilitation plan or habilitation plan, but that they have not received any such plan. In addition, between 3 and 4 per cent state that they have an individual rehabilitation plan with which they are not happy. The proportions of respondents who state that they have received an individual rehabilitation plan with which they are happy and those who *completely* lack a plan or are dissatisfied with the plan they have are roughly equal.

It is worth noting that as many as 15 per cent of members of the Swedish Federation of People with Mobility Impairments and 18 per cent of the members of the Swedish Association of Hard of Hearing People who need rehabilitation/habilitation answer that they do not know whether they have received an individual rehabilitation plan.

According to the National Board of Health and Welfare report "Equal social services?", it is found that more women than men receive rehabilitation benefit for work-oriented rehabilitation. However, women are granted shorter periods of both work training and studies than men (government bill 2003:04:1). The costs of training courses for women were less than one third of the cost for men's training courses. Women were allowed both work training and studies at a later stage in the sickness period as compared with men.⁸⁴

⁸² Access to habilitation and rehabilitation for adults with disabilities an appraisal' the National Board of Health and Welfare 2004

⁸³ Access to habilitation and rehabilitation for adults with disabilities? an appraisal' the National Board of Health and Welfare 2004

⁸⁴ Equal social services. The National Board of Health and Welfare 2003, page 39.

Rehabilitation for elderly people with disabilities

One group with particularly prominent needs for rehabilitation initiatives is the elderly. A report from the Stockholm county elderly centre⁸⁵ was presented in March 2004. This report shows how individual elderly people with differing disabilities fall outside all combined healthcare and medical treatment, including rehabilitation. Difficulties arise in meeting the needs of the elderly when one and the same individual has needs that should be met by both the Social Services Act and the Healthcare and the Medical Treatment Act. The study that the Swedish Federation of People with Mobility Impairments conducted among members over the age of 65 shows that 42 per cent do not receive rehabilitation, e.g. physiotherapy and warm baths, in the home district or receive rehabilitation on a very limited scale. 90 per cent have no possibility of annual rehabilitation in rehabilitation clinics.

Priorities

In the prioritisation government bill⁸⁶, habilitation and rehabilitation have been placed in priority group II with regard to prioritisation at policy/administrative level and also in relation to prioritisation in clinical activities. This indication of habilitation and rehabilitation initiatives also needs to be highlighted in practical everyday work in the county council as such initiatives are often given lower priority when resources are scarce. The prioritisation principles decided on by the Swedish Government are not applied. Direct acute handling is very good, but there are then deficiencies in subsequent rehabilitation. Rehabilitation is started too late and is not co-ordinated to a sufficiently high level. The medical development that has resulted in ever shorter inpatient care times also results in difficulties through ever greater rehabilitation needs being transferred to outpatient care.⁸⁷

The Swedish Disability Federation considers that:

- The county councils needs to intensify their work in identifying habilitation and rehabilitation needs in individuals and groups of people with disabilities and build up systems for following up results.
- In order to be able to obtain a comprehensive view of habilitation and rehabilitation, and also to be able to develop and improve the rehabilitation and habilitation initiatives, the county councils' appraisals and reporting systems must also cover rehabilitation and habilitation initiatives for women, men, girls and boys with disabilities.
- The county councils need to become more aware of the legal obligation of working with individual habilitation and rehabilitation plans and of the fact that

⁸⁵Gurner, U, Fastbom, J, Österman, J: We don't have time? Call the emergency department! Stockholm, Stockholm county elderly centre' 2004. (Reports 2004:1.)

⁸⁶Priorities within healthcare and medical treatment: Government bill 1996/97:60.

⁸⁷The National Board of Health and Welfare: Disability care - Report of the situation in 2004, 2005-131-6

this instrument needs to be used to a much greater extent than is currently the case.

- The prioritisation decision must provide guidance in all planning in healthcare and medical treatment and must apply to all initiatives: care and treatment, habilitation, rehabilitation, dental care and medicines.

4 Lack of co-ordination

The members of the Swedish Disability Federation include many who are aware of how valuable effective collaboration can be. At the same time, many of us have to face the consequences of shortcomings in this collaboration. People with chronic diseases and disabilities are often dependent on initiatives from many different care and service providers at the same time or as different links in a care-providing chain or rehabilitation process. This places considerable demands on planning and co-ordination of the initiatives.

The appraisal of disability care⁸⁸ conducted by the National Board of Health and Welfare shows that co-ordination between different bodies is lacking or works poorly. When individuals need support and servicing from a number of different operations within a local authority, there is sometimes a lack of co-ordination and an overall vision. Individuals must often themselves make contact for help and support. There are also deficiencies in the co-ordination between local authorities/county councils and other authorities. A lack of co-ordination means that individuals fall between two stools, as indicated by many people in a study conducted by the Swedish National Social Insurance Board.⁸⁹

The Swedish Disability Federation feels that people with disabilities need to be very strong and healthy to cope with being sent around between primary care, county medical treatment, specialist care, adult habilitation, assistive device centres, local authority and external executive agencies.

To ensure quality and continuity in a co-ordination process, everyone who comes into contact with care and rehabilitation care should be offered a co-ordinator. In addition, individual plans, appropriately adopted and for a larger group than covered at the present time, can be an important tool in bolstering the individual's position and gaining an overview of the responsibility of authorities involved. If the overall situation is to work for the individual, it is also essential for the various authorities to co-operate.

⁸⁸ The National Board of Health and Welfare' Disability care - Report of the situation in 2004, 2005-131-6

⁸⁹ The social insurance book 2002, the Swedish National Social Insurance Board

The Swedish Disability Federation considers that:

- The various authorities and players involved in care, habilitation and rehabilitation must find a system for collaboration.
- Shared responsibility between various responsible authorities leads to individuals falling between two stools. In a legislative context, specifying that various responsible authorities share responsibility should therefore be avoided.
- If there is shared responsibility, people covered by LSS must be given a named co-ordinator.
- The county councils need to become more aware of the legal obligation of working with individual habilitation and rehabilitation plans and of this tool needing to be used to a much greater extent than is currently the case.
- Guidelines relating to an effective care-providing chain, care and collaboration and also to the substance and quality of habilitation and acute and continuous rehabilitation should be drawn up.

5 Conclusions and recommendations

Information in this article shows that people with disabilities do not enjoy the highest attainable standard of physical and mental health.

There are sharp differences in access to care and quality of care in different parts of the country. It is very important that people can access care and rehabilitation regardless of where in the country they live. In addition, the prioritisation principles for rehabilitation decided upon by the Government are not applied. As a rule, immediate acute treatments are very good, but the subsequent rehabilitation process then shows shortcomings. Rehabilitation, support, service and assistive devices are essential for people with disabilities to be able to participate in society and contribute to their own care. It is extremely important that existing laws are observed and that the co-ordination between the players involved is improved.

The starting point for the recommendations below is General comment no. 5, General comment no. 14 and UN standard rules 2 and 3.

The Swedish Disability Federation recommends the Swedish State to:

- Ensure that parliamentary decisions, laws and/or central agreements are in practice followed so that Sweden can secure effective healthcare and medical treatment.

to be continued on next page

- See to it that the collaboration is reinforced between players in the field of care, habilitation, rehabilitation, social insurance offices and labour market participants.
- Safeguard the right to care outside one's own county council area if first-class competence is lacking within one's own county council area.
- Work to ensure that national guidelines for healthcare and medical treatment are drawn up for all diagnosis groups to secure higher-level quality for the care and equivalent care initiatives throughout the country.
- Ensure that everyone receives the necessary habilitation and rehabilitation regardless of where in the country one lives and independently of sex.

Article 13

1 Primary education

In Sweden, a compulsory schooling requirement applies. This means that education is compulsory for all children for years 1 – 9. Despite this, Sweden still does not have a school for everyone. A quarter of pupils in compulsory education do not attain the required level to pass all subjects.⁹⁰ A survey covering people with a number of disabilities, namely mobility impairments, ADHD, DAMP, Asperger's syndrome, visual impairments, people who are hard of hearing and with Tourette's syndrome, showed that the pupils had much greater difficulty achieving targets than the average pupil. Barely one half of pupils with ADHD, DAMP and Asperger's syndrome were expected to attain the targets in Swedish, mathematics and/or English in year 9 of compulsory education.⁹¹ Nearly half (47 per cent) of applicants to the National Upper Secondary School for pupils who are hard of hearing in Örebro (RGH) 2004 did not pass the core subjects of Swedish, English and mathematics.⁹²

Section 3 describes the reasons for pupils not achieving the targets for compulsory education.

2 Secondary education

Under the law, all local authorities in Sweden are obliged to offer all pupils who have completed compulsory education an upper secondary school education. Upper secondary education can be offered in three different programmes: national, specially designed and individual programmes.

National programmes are three-year, provide a broad basic education and provide a qualification to study at university or college.

Specially designed programme can meet local and regional educational needs. A specially designed programme is equivalent to a national programme in terms of the level of the education and the numbers of hours involved.

Individual programmes can be designed to meet the individual pupil's needs for skills and may therefore vary in length and content. The objective is for the pupil

⁹⁰ The Swedish National Agency for Education assessment of the situation in 2004 concerning preschool activities, schoolchildren care, schools and adult education, REPORT 249, 2004

⁹¹ Three magic G's – School initiatives for pupils who are hard of hearing, the Swedish National Agency for Education, 2001

⁹² 2005 annual report of the Swedish Association of Hard of Hearing People, truth and consequences of the situation of the hearing impaired in Sweden

subsequently to go on to a national or specially designed programme. Training in the individual programme does not provide competence for higher-level studies.

One report⁹³ shows that at upper secondary school level, 40 per cent of pupils with mobility impairment and pupils with ADHD, DAMP and Asperger's syndrome followed the individual programme. Of these:

- 27 per cent were already qualified for the national programmes, but were still receiving teaching on individual programmes
- 12 per cent were expected to qualify for a national programme,
- just over 50 per cent were expected not to qualify for a national programme.

Of pupils within the above group of pupils who went on a national programme, only 40 per cent were expected to attain basic competence for college studies.

Pupils with mobility impairment achieved the compulsory education targets in line with the national average. Nevertheless, nearly two thirds of the pupils went on to individual programmes at upper secondary level, of which only a few were expected to qualify for a national programme.

The next section describes the reasons why pupils do not cope with the education at upper secondary school.

3 Deficiencies in compulsory and upper secondary school education

Participation in the education

There are a number of reasons why pupils with disabilities do not achieve the targets in compulsory and upper secondary education. One reason is that many people cannot participate fully in schooling. In the report by the Children's Ombudsman entitled "Unseen, but still there"⁹⁴, 36 per cent of pupils with DAMP/ADHD state that they cannot take part in all subjects. The figure for pupils with visual and hearing impairment is 13 per cent for both groups.

One interview-based study⁹⁵ shows that pupils with mobility impairment often cannot take part in sports days or teaching in aesthetic subjects and athletics.

Support initiatives

The study entitled "Three magic G's" shows that schools deploy most resources on pupils with visual and diagnosed disability. The initiatives for these pupils were essentially the same, regardless of the pupil's diagnosis. The pupils were offered a

⁹³ Three magic G's - School initiatives for pupils with disabilities, the Swedish National Agency for Education, 2001

⁹⁴ Unseen but still there, report by the Children's Ombudsman to the Swedish Government, 2002

⁹⁵ Children and young people with mobility impairment – a project description, Maare Tamm, Save the Children Sweden, 2001.

more relaxed pace and/or greater adult support, which they were considered to achieve by taking part in small groups, being taught by special teachers or having access to assistants.

The schools applied an "either/or policy": either massive support initiatives or virtually nothing at all. The results show that schools need to develop ways of meeting the requirements of pupils who have little or moderate need of support initiatives. The study also shows that support for pupils with disabilities varies sharply between schools and programmes. The support is often restricted to the subjects of Swedish, mathematics and English and may consist of more time for completing the course, time which is then taken from other courses. In certain cases, this can mean that pupils cannot obtain the school-leaving certificate.

Pupils who, owing to psychosis or other mental disability, have been off school for a while often do not receive the necessary support and reception when they come back. Both competence on the part of teachers concerning how they should handle pupils and awareness of classmates about how they should receive the pupil are therefore very important for these pupils being able to resume and complete their education. For example, the Swedish Epilepsy Association states that fear and ignorance can make schooling difficult for pupils with epilepsy.

The teaching situation

The teaching situation is lacking. In one survey⁹⁶ that describes the school situation for integrated senior-level pupils who are hard of hearing, it emerges that half the pupils do not receive any extra support and usually no individual action programme.

The study also shows that more than three in four (78 per cent) of the integrated pupils who are hard of hearing are in classes with more than 20 pupils. Nearly half are in classes with more than 25 pupils. Large school classes are negative for many pupils who are hard of hearing. Opportunities for communicating with teachers and classmates are reduced in large classes.

In his study entitled "Unseen, but still there", the Children's Ombudsman asks pupils whether they are treated differently from their classmates. Nearly one quarter of the pupils answered in the affirmative. Many of the answers show that children with disabilities receive positive special treatment. For example, they are given more attention. The negative aspect that emerges has to do with the fact that they are separated and placed in other teaching facilities or pitied. Being regarded as being feeble-minded and being given tasks below one's capabilities is experienced as insulting.

Assistive devices and teaching aids

There is a lack of assistive devices in schools. One in every three children with mobility impairment disabilities and one in four children with visual impairment or DAMP/ADHD state that they are not given adequate assistive devices. This

⁹⁶ 74 votes on school – Being hard of hearing and individually placed in year 7, 8 or 9. Survey of pupils in counties prescribed hearing aids, Håkan Bergkvist, the Swedish Institute for Special Needs Education 2001

generally applies more frequently to girls than boys. In the so-called "Living conditions project"⁹⁷, parents of children with mobility impairment were asked whether their children were given the assistive devices they need. Only 44 per cent answered in the affirmative and were happy with the various assistive devices. For further views on the assistive devices situation, see article 11.

A study of teaching aids and assistive devices for visually impaired pupils⁹⁸ showed that it often takes a long time to have the teaching aids delivered. Sometimes they can arrive so late that they are no longer needed.

For pupils with reading and writing difficulties/dyslexia, the situation is even worse. They have no statutory right to literature in accessible media. This applies to all types of schooling except for studies at college and university.

In Government bill 1993/94:100, it was identified that the need for scanned teaching materials was so great that production could take place on a commercial basis. Since then, more than 10 years have passed without anything happening.

Study guidance

It is set out in Chapter 5 (1) of the Compulsory Education Order that if a pupil needs specific support measures, the principal must ensure that an individual action programme is drawn up. The pupil and the pupil's custodial parent must be given an opportunity to take part when the programme is devised. Similar provisions exist for upper secondary schools and special schools. The Swedish Disability Federation has identified that many pupils with disabilities nevertheless do not have an individual action programme.

Study and vocational guidance are of extra importance for pupils with disabilities. They can find it more difficult, for example, to secure summer jobs and gain experience of the labour market, which can in turn affect the choice of training and occupation. Study guidance is then of the greatest importance. The study adviser also plays an important part in the development of action programmes. The Swedish Disability Federation fears that study and careers guidance is not provided to the extent needed by pupils unless the matter is regulated in the Schools Act.

The Swedish Disability Federation considers that:

- It is unacceptable that compulsory-level and upper secondary pupils cannot take part in all education. The schools need increased teaching resources that make it possible to plan the teaching in such a way that all pupils take part.

⁹⁷ The living conditions project – a study of living conditions for families with children with mobility impairment, Karin Paulsson & Åsa Fasth, the Swedish National Association for Disabled Children and Young People

⁹⁸ That's how the integrated school works – an interview-based study of the Swedish Association of Visually Impaired Youth, Åsa Pehrsson, 2000

- All schools and training authorities must be accessible to all.
- An accessible school is a school with both physical and social accessibility. Every pupil must – based on his or her needs – be given access to the adapted teaching materials, equipment, assistive devices and personnel support required to be able to take part in the education. It is of the utmost importance that all pupils receive the support they need in school.
- Good teaching materials should be produced in an alternative format right from the start.
- A major task for the State institute given responsibility for teaching materials for people with disabilities is to endeavour to ensure that fully accessible teaching materials are developed.
- Pupils' rights to adapted teaching materials must be enshrined in the Schools Act.
- The right to action programmes in both compulsory-level and upper secondary education must be reinforced and regulated in the Schools Act.
- Action programmes must be developed together with the pupil and, where necessary, the parents. The measures should be based on the pupil's individual needs. School staff who assist in the development of action programmes must have special teaching competence.
- Action programmes must be open to appeal in the administrative courts with regard to
 - the right to have them established,
 - the quality of the investigation,
 - decisions on support not complying with the action programme set up.
- Pupils' rights to study and vocational guidance must be regulated in the Schools Act.
- Study and careers advisers must have a high level of competence concerning disabilities or be entitled, where necessary, to acquire such competence.

4 Special schools and hearing classes

For pupils who are hard of hearing or deaf, various types of schooling are available: schooling in an "ordinary" class, hearing classes or within a special school. Out of a total of 5700 children and young people aged 6-15 years old, the vast majority, 82 per cent, are individually integrated in an "ordinary" class. This means that most who have hearing aids and many with cochlea implants attend the local authority school – many without the necessary adaptations that make it possible to participate in the school.

The five regional special schools for pupils who are deaf or hard of hearing are attended by 542 pupils, including 85 with cochlea implants and 166 with impaired hearing (HRF 2005).

Local authority hearing class schools that receive grants pursuant to the Special Initiatives in Schooling Order are attended by 302 pupils with hearing aids, 38 with cochlea implants and 22 deaf pupils.

Common to all pupils in special schools and to many individually integrated pupils is the need for schooling with effective communication, adapted teaching and teachers with specific knowledge of the pupils' needs. Today most of them attend school under the same conditions as the hearing pupils, with inadequate adaptations. As many as 47 per cent of applicants to the National Upper Secondary School for the Hearing Impaired in Örebro in 2004 had not passed the core subjects of Swedish, English and mathematics. Two thirds of applicants to the National Upper Secondary School have had an integrated schooling.

Integrated schooling

As already described, there are major deficiencies within compulsory education. Over 50 per cent of all pupils who are hard of hearing - i.e. all children with hearing aids or cochlea implants and the deaf – need adapted teaching in compulsory schools. However, only 18 per cent receive such schooling. One in every five pupils in integrated education rarely or never hear what their classmates say (according to the Swedish Institute for Special Needs Education 2001). Just over 40 per cent of the pupils do not have or do not use hearing equipment at school. Over 70 per cent state that the teacher rarely or never passes the microphone around in class or repeats answers.

For the individual, "failure" in ordinary schools means gaps in his or her knowledge and/or a lack of language development that can be difficult to make up in current adapted types of school. The consequence is poor school results for the individual pupil.

Hearing classes

Hearing classes are special teaching groups with an adapted physical environment, teaching and hearing equipment. Hearing classes may exist at regional or local authority level. Larger units with hearing classes are called hearing class schools. The hearing class schools belong to the local authority compulsory school, but are financed partly from State funds and partly by the pupils' home local authorities. There is no entitlement for pupils who are hard of hearing to choose hearing classes. Formulations in the current Schools Act do not cover hearing classes and therefore do not cater for all the hard of hearing prospects of equal schooling. The individual pupils are entirely dependent on the local authority's good will, knowledge and finances.

There is no combined knowledge/information concerning school results in hearing class schools. The Swedish Disability Federation's experience of hearing classes is, however, good. All pupils who are hard of hearing or deaf must be given the right to choose this kind of schooling.

Special schools

In Sweden, there are six State special schools; five of these are regional and the other one has a national intake with the target group comprising deaf pupils with intellectual disabilities. The task of the special school is to give pupils who are deaf and hard of hearing an education that must as far as possible match that provided in compulsory schools, but which is tailored to each pupil's requirements. Pupils can now, within this form of schooling, choose between being taught either in sign language or with speech/hearing equipment.

Special schools are funded by the State and the pupils' home local authorities. One of the aims of the schooling is for every pupil, on leaving the special school, to be bilingual at the end of year 10, i.e. be able to read sign language and read Swedish, express thoughts and ideas in sign language and in writing.

However, a total of only 54 per cent of pupils in all years at special schools state that they are bilingual⁹⁹.

The special schools authority has commissioned a study of the reading abilities of pupils in special schools¹⁰⁰. The findings of the study show that the younger pupils who are hard of hearing obtain results that are in line with reading development in pupils who are hearing. Among the older children, we find that, compared with pupils who are hearing, reading development varies. Reading is generally slower and the proportion of pupils with low marks for reading comprehension is substantially higher compared with pupils who are hearing. The group averages from the reading speed test are significantly lower than for hearing pupils.

Only 40 per cent of pupils in special schools qualify for the national programme at upper secondary level.

Choice of school types

It is not usually the children's needs that determine which pupils attend adapted types of schools. Schooling may instead depend on which types of school happen to exist in the home local authority, the willingness of the home local authority to pay for schooling in another local authority, different advisers' attitudes to school alternatives and so on.

The consequence of all these shortcomings is very poor school results – despite the fact that the children who are hard of hearing are just as gifted as other children.

The Swedish Disability Federation considers that:

- Pupils who are hard of hearing, deaf and deaf-blind have special communication needs and it is therefore of the utmost importance that these pupils can choose an adapted type of school. Effective communication is

⁹⁹ Pupils and parents come up with ideas about special schools, Full report for the spring term 2003 for: the Birgitta School, the Kristina School, the Manilla School, the Väner School, the Åsbacka School and the Östervång School. A report by HANDU – on behalf of the Special Schools Authority

¹⁰⁰ Reading development in pupils who are hard of hearing, years 2-6

required for pupils to be able to be given a worthwhile schooling and be given an opportunity of achieving good results at school, in higher education, at work and in other life situations.

- Pupils' right to choose hearing classes must be enshrined in the Schools Act.
- Children/young people who are hard of hearing must be given an opportunity to learn sign language as part of the school's activities. This applies regardless of the type of school.

5 Special schools

Basic special schools

In Sweden, children and young people considered incapable of achieving compulsory school and upper secondary school targets owing to intellectual disability are entitled to education in special schools. This applies also to pupils who have a substantial and permanent talent-related disability owing to brain injuries or who have autism or autism-like conditions. Special schools are deemed to include compulsory special schools and upper secondary schools. Since 1 January 1996, all special schools and the entire special adult system have been municipal.

In recent years, the increase in pupil numbers in special schools has been sharp, but varies between the local authorities. Roughly three per cent of pupils in Sweden, i.e. just over 20 000 children and young people, attend special schools¹⁰¹. There are a number of reasons¹⁰² for the increase in pupils in special schools, including deficiencies in the study procedure within local authorities and a lack of resources in compulsory schools.

Acceptance by special schools must be preceded by a strict test. The Agency for Special Schools, i.e. the local authority's committee for children and young people or equivalent, decides whether a child should be offered a place in this kind of school. More and different officials from before have thus been given responsibility for assessing who belongs in special schools.¹⁰³

The assessments have thus also been performed with less expertise. It is noteworthy that a large proportion of principals and administrative managers (86 and 63 per cent respectively) are unfamiliar with and/or have not read the advice of the Swedish National Agency for Education concerning routines for investigation and

¹⁰¹ Assessment of the situation by the Swedish National Agency for Education 2002

¹⁰² SOU 2003:35, For the one I am – on education and educational disorders, the Carlbeck Committee

¹⁰³ Ibid

decision-making of acceptance by compulsory special schools.¹⁰⁴ Many teachers in special schools state that they teach children who do not have intellectual disabilities.

Studies show that children with immigrant backgrounds are over-represented in special schools and that they are accepted by special schools on different grounds from Swedish children.¹⁰⁵ Most Swedish pupils in special schools have clearly established medical disabilities, whereas special school pupils with an immigrant background more frequently have more unspecified diagnoses. In one interview-based study¹⁰⁶, many parents express uncertainty about placement in a special school, and a number of parents have also actively worked against it. Parents often experience a lack of collaboration between school authorities and parents.

Trial scheme with a greater influence over schooling for children with intellectual disabilities

Since 1996, a trial scheme has been going on in which parents have increased influence over schooling for children with intellectual disabilities. The trial scheme is regulated in a special Act that was in force until the end of June 2005 (2000:446). The project has subsequently been extended to the end of June 2008. The Act means that a child's guardian is always entitled to decline acceptance of the child by the compulsory special school. The guardian is also entitled to require that a child who has been accepted by a special school be transferred to the compulsory school. The Swedish Disability Federation considers that it is parents, and not society, who should have ultimate responsibility for the child's placement in the school.

5.1 A lack of resources in compulsory school

Substantial savings in the local authorities and their schools have meant that pupils do not receive the same support as before in compulsory schools. Compulsory schools do not have adequate opportunities for being able to take on and teach pupils with intellectual disabilities.

One way of obtaining special support is then to be accepted by a special school. Parents can therefore feel compelled to accept special schools for their children because it is the only way of securing extra resources¹⁰⁷.

The Government official report entitled "For the one I am"¹⁰⁸ shows that many local authorities lack overall strategies for education in special schools. This creates

¹⁰⁴ Assessment of the situation by the Swedish National Agency for Education 2004

¹⁰⁵ Bel Habib, Ingela (2001). Pupils with an immigrant background in special schools: special teaching or disciplinary power. MHS – Research report.

¹⁰⁶ For the one I am – on training and intellectual disabilities, the Carlbeck committee, 2003:35, p. 103

¹⁰⁷ SOU 2003:35, For the one I am – on training and intellectual disabilities, the Carlbeck committee, p. 85

¹⁰⁸ For the one I am – on training and intellectual disabilities, the Carlbeck committee, 2003:35, p. 115 *et seq.*

problems for principals, who have also in many cases been given responsibility for special schools without having previously had any experience and without opportunities being given for skills development. Assessments of quality in special schools show that staff place a greater emphasis on security and care than on knowledge and challenges. In special schools, too, many pupils do not have an individual action programme.

The Swedish Disability Federation considers that:

- Targeted initiatives are needed to increase the awareness of the responsible authorities and the schools concerning the regulations that govern the activities of special schools.
- It should be enshrined in the Schools Act that placement in special schools must always be preceded by a thorough and all-round investigation.
- Parents of children who are offered placed in special schools must always be given proper information on the various types of schools and on what short-term and long-term consequences the choice of school type may have.
- Where a choice of school type is made for pupils with a foreign background, interpreters must always be used. To reduce the risk of the pupil being placed in the wrong type of school, repeat assessments need to be conducted.
- The trial scheme with greater parental influence must become a permanent operation.
- Teachers who teach within compulsory special schools and upper secondary special schools must have basic training and relevant special teaching competence.
- The right to an individual action plan for both compulsory special schools and upper secondary special schools must be enshrined in the Schools Act.
- When the individual action plans are drawn up, it is important that the need for aptitude support is taken into account.

5.2 Upper secondary special schools

The chapter above relating to special schools also covers upper secondary special schools. However, we would like to provide a little additional information on upper secondary special schools in a separate section.

Upper secondary special schools offer national, specially designed and individual programmes in a similar way to upper secondary schools. National programmes are fewer in number than in upper secondary schools and focus on various vocational preparations. The Agency for Special Schools decides whether a pupil should go on a national, specially designed or individual programme. There is a lack of major assessments of quality in upper secondary special schools, and so it is difficult to make general pronouncements on their results. The Education Inspectorate has, however, criticised deficiencies within upper secondary special schools which mean

that not everyone receives the education to which they are entitled. Choices for pupils who have been considered capable of going on a national programme are often limited by local authorities only offering one or a few of the upper secondary school's eight national programmes.

The Swedish Disability Federation considers that:

- Consultation must take place with the pupil and the pupil's guardian concerning whether a pupil should go on a national or specially designed programme or an individual programme.
- The school should have responsibility for the consultation functioning. It is important that guardians be given information on what options exist before the consultation takes place and also that the consultation is documented.
- The range of programmes must increase so that pupils can be given options.

6 Colleges and universities

Statistics from 1999 show that students with disabilities are an under-represented group out of the total number of students. According to the college survey conducted by the Swedish Disability Ombudsman in 2005, it is apparent, however, that the number of students with disabilities is rising. Over the last year, there has been an increase of 30 per cent. The Swedish Government's aim is for 50 per cent of an age group to go on to higher education. According to a recently published report, however, only 10-15 per cent of students who are hard of hearing go on to higher education, for example¹⁰⁹.

Study guidance and information

People with disabilities often face more problems than others when they consider commencing studies. These concern not only support initiatives and the possibility of obtaining assistive devices during the studies but also how they will manage financially. An advisor with sound knowledge of the conditions of people with physical impairments is extremely important if people with disabilities are to have the necessary courage/willingness/capability to begin studying at college and university. The study by the Swedish National Agency for Higher Education described below shows that, before commencing studies, many pupils have not received information on what support they can obtain. Many of the young people interviewed stressed the lack and the importance of actively targeted information in upper secondary schools. Only about one quarter of those interviewed had received any information on available support schemes at university and college.

The college test

It is not uncommon for people with disabilities to have bad experiences from earlier schooling and studies. All the chapters above shed light on the difficulties experienced by pupils with disabilities in achieving college and university

¹⁰⁹ 2005 annual report of the Swedish Association of Hard of Hearing People

competence. As so many types of school are not completely accessible to people with disabilities, it is of the utmost importance that these pupils, too, can take the college test. It is currently possible only for people with moderate vision or dyslexia to sit an adapted college test.

Support schemes

The support schemes that universities and colleges have developed make it possible for many people with disabilities to engage in higher-level studies. An important question in this connection is whether the support schemes are appropriate or whether there are deficiencies in the support schemes that contribute to students with disabilities being unable to benefit from higher education.

In the publication "Higher education and physical impediments", the Swedish National Agency for Higher Education compiled a survey and elucidated facts from other studies conducted. The survey related to students who benefited from support schemes from the colleges. It is apparent from the publication that about 75 per cent of students benefiting from support schemes considered accessibility to be good or very good, while around 25 per cent considered it to be poor or very poor. Accessibility to studies is in this context understood to mean that students with disabilities should be able to benefit from the teaching in the same way as students who do not have disabilities. Not only physical accessibility is therefore involved, but so too is the possibility of being able to benefit from the teaching with the aid of, for example, support schemes. Nearly two thirds of students considered that they did not or partly did not have access to the assistive devices that they needed.

Nearly all colleges/universities have appointed co-ordinators who ensure that students with disabilities benefit from adaptations and support, including sign language interpreters, senior teachers, writing help adapted to examinations, etc. However, the support varies sharply between different colleges, partly owing to the fact that seats of learning go in for co-ordinator services differently. Another major problem is that many colleges are not getting better at working with a number of groups of people with disabilities. Many with medical (e.g. episodic stomach and bowel diseases, asthma and allergies), cognitive and mental disabilities do not receive so much support nowadays.

Equal treatment plans

As described in article 2, the Equal Treatment of College Students Act has been in force since 1 March 2002. Under this Act, colleges must work to ensure the equal rights of all students. Each year, every college must draw up a plan to prevent discrimination.

In 2005, the Swedish Disability Ombudsman conducted a survey of the country's colleges and universities. Of the 59 seats of learning that answered the survey, it is apparent that:

- One quarter have not drawn up any plans at all for their work with equal treatment.
- Many of these do not even know that the requirement for a plan is enshrined in law.
- Of the 44 seats of learning that have a plan, many fail to address important issues for students with disabilities. Only just over one half

address the introduction to studies, types of examinations and the actual teaching situation itself from their point of view.

- Barely one half of the seats of learning that have drawn up a plan address issues of recruitment and admission from the disability perspective.
- Only a third of the plans address timetabling. This may, for example, concern whether the timetable allows students with mobility impairment to move between the teaching facilities.
- Less than half of the seats of learning deal with how the improvements should be implemented.
- Only 1 in 5 seats of learning indicate when the measures should be implemented and link them to the budget.
- Only 1 in 5 seats of learning state in their plans that they are considering collaborating with representatives from the disability movement.

The Swedish Disability Federation considers that:

- The Swedish Government must work to ensure that study advisers and employment services at colleges and universities are given more information on disabilities, attitudes and treatment and accessibility.
- The Swedish Government must work to ensure that the college education for study advisers must contain 5 points for disability issues / attitudes and treatment knowledge and that continuing training is developed in the subject for those people already working as study advisers. For example, the Sisus treatment programme may be adopted in the continuing training of advisers.
- The study advisers must become easier to visit and also pass on information to people with various disabilities.
- The college test needs to be adapted to students with special needs.
- The seats of learning need a better understanding of what is required to increase opportunities for everyone to study. It is particularly important that the schools' management support the work with the equal treatment plans and decide that accessibility should be improved.

7 Local authority adult education

Adult education exists for adults who have not completed their compulsory or upper secondary education or who want to supplement it.

As described in article 2.1, there are no confirmed figures on how many of those who do not complete their upper secondary education have disabilities. However, in 2000 the knowledge enhancement committee commissioned a special study in "Knowledge development: lifelong learning" (SOU 2000:28). It is apparent from this (Table 13.1) that among people with disabilities in the 20-49 year-old age group, there are 64 per cent who do not have up to three years of upper secondary

education. This can be compared with the upwards of 50 per cent (50.5 per cent) who do not have up to three years' upper secondary education in the same age group among people without disabilities.

Recruitment and Recruitment contributions

Active recruitment, outreach work and guidance are key to increasing the number of adults with disabilities in adult education. Nevertheless, the Swedish Institute for Special Needs Education report entitled "Adult learning" (2004) shows that only one half of the local authorities asked work with direct recruitment initiatives for adults with functional impairments. The report also shows that the local authorities lack a quality review and working methods. Only one in 63 of the local authorities questioned, for example, require quality reports from their training suppliers. When the multiyear Knowledge Enhancement initiative was assessed by the Swedish National Agency for Education, it was found that fewer people with disabilities than others were reached.

In 2003, the Recruitment Contribution was introduced as a targeted initiative to reach groups that are difficult to recruit. The assessment of the first year with the recruitment contribution was published on 1 June 2004¹¹⁰. The assessment showed that only 2.7 per cent of the contribution went on people with disabilities. Only 60 per cent of the local authorities had consulted with disability organisations prior to the drafting of guidelines. 36 per cent of the local authorities had used disability organisations as a channel for recruitment. "The local authorities have not reached people with disabilities to any great extent" was the verdict of the Swedish National Agency for Education in the assessment.

The Swedish Disability Federation would stress that recruitment work has many sides to it. A number of bits of the puzzle such as study finances, flexible adaptation, housing, possible assistance and the subsidised transport service often need to fall into place for the study situation to work.

Lack of accessibility

In spring 2005, the Swedish Disability Federation commissioned a study of adult education quality in several local authorities chosen at random. Only one of the local authorities asked had a long-term strategy for accepting students with functional impairments. The study shows that in some local authorities it is not even possible for people with mobility impairment to enter via the main entrance. Less than half those questioned had hearing loops for people who are hard of hearing, contrast markings for people with visual impairment or a recommended perfume-free environment for people with allergy. Only one of the local authorities questioned had routines for sign language interpretation. The lack of accessibility of local authority adult education means that many people with disabilities are forced to forego adult education, to which all people are entitled under Swedish law.

¹¹⁰ Assessment of recruitment contributions to adult students. The first contribution year 2003, the Swedish National Agency for Education 2004

The Swedish Disability Federation considers that:

- Local authorities must work more actively to identify methods that can improve recruitment and outreach activities aimed at people with disabilities.
- Adult education must be equally accessible to all. All adult education organisers must strive to ensure that people with disabilities are able to participate in adult education under the same conditions as all others.
- The Swedish National Agency for Education must develop better methods for their supervisory responsibility with regard to the local authorities' work with respect to pupils/students with various disabilities. The supervision should also include making sure that the information on the range of courses is available to all.

8 Education for adults with intellectual disabilities

Adult education for people with intellectual disabilities, Särvox, is a specific form of schooling aimed at adults with intellectual disabilities who want to supplement their education. An adult eligible to apply for such education does not have any unconditional entitlement to basic education. Conversely, an eligible applicant for basic adult education has an unconditional right to adult education of this kind (Chapter 11 (10) and (8) of the Schools Act).

Adult education for people with intellectual disabilities is differently structured in different local authorities. Generally speaking, the training courses, in terms of teaching hours, are very short. On average, every pupil given adult education for people with intellectual disabilities has 2.7 hours of teaching each week. The number of students under the Särvox scheme has grown over the last few years, but the number of teaching hours has increased only marginally.

It is emphasised in the government bill for "Adult teaching" that individual study plans are important. Despite this, pupils covered by the Särvox scheme are not entitled to individual study plans. The Local Authority Adult Training Ordinance does not regulate the individual study plan for adult students, but corresponding rules are absent from the Särvox Ordinance.

Adults with intellectual disabilities need to be given an opportunity to study in order to maintain or acquire knowledge. This is especially important when many have poorer opportunities than other adults to practise their skills and keep them alive.

The Swedish Disability Federation considers that:

- Adults with intellectual disabilities must have the same opportunities for basic adult education as other adults. This right must be enshrined in the Schools Act.

9 Adult education colleges

Another form of education for adults over 18 years of age is education at adult education colleges. Distinguishing features of adult education colleges as a type of school are that it is attempted to have fewer and more unified study groups, that studies often take place across subjects in project form and that students' needs, previous knowledge and experience are taken as the basis. This gives course participants considerable opportunity to influence the focus and content of the studies together. In studies within adult education colleges, the student can take both general and special courses. The general courses can provide both upper secondary and university competence.

The Adult Education Council distributes State subsidies to all adult colleges. The Adult Education College allocates around 10 per cent of its State subsidies to extra teaching initiatives for immigrants and for participants with disabilities. The initiatives may consist of better teacher ratios, co-ordination, careers guidance and extra school welfare officer/psychologist initiatives. 14-15 per cent of students in adult education have disabilities.

The disability movement is generally very positive about the activities of adult education colleges. The problem identified (particularly by the young people's organisations) is the lack of freedom of choice for the individual. Various adult education colleges specialise in certain groups of students. Individuals are therefore sometimes asked to move to certain places to be able to study. According to "Adult education in a time of great changes"¹¹¹, most of the adult education students with disabilities participated in courses with only or a majority of students with disabilities.

One circumstance that poses a problem is that most county councils do not provide personal assistive devices for study at adult education colleges¹¹². The regulations relating to the education system should be reviewed so that they harmonise with one another. This would avoid many of the current "tugs of war" between different sectors of society.

The Swedish Disability Federation considers that:

- All adult education studies should be accessible to everyone wanting to study or participate.
- There is a danger of people with disabilities being segregated and not being seen as individual students in need of certain support, usually of a teaching-related or technical kind. The diversity is emphasised as characteristics of adult education and this should also apply to people with different functional conditions.
- Students at adult education colleges should have the same rights as students in other adult education. This applies, for example, to the right to assistive devices and literature.

¹¹¹ Adult education in a time of great changes SOU 2004:30

¹¹² The assistive devices report SOU 2004:83

10 Free schools

Alongside the public schools system, there are independent schools, known as 'free schools'. These have a different principal (owner) from local authorities or county councils. These independent schools are supposed to be open to all. A clause in the Schools Act means that it is nevertheless still possible for a free school to deny a student entry if he or she needs substantial extra resources. This may, for example, be if the student needs an assistant or if the school has to be converted.

The main purpose of free schools is to increase freedom of choice for the individual. For pupils in need of support, the increase in the number of free schools has, if anything, curtailed freedom of choice as these pupils do not have access to free schools.

The Swedish Disability Federation considers that:

- The clause in the Schools Act must be removed so that free schools have no possibility of being able to refuse to take on pupils with disabilities. All pupils must have the same opportunity of education.

11 Right to choose schools

Pupils in special schools have much poorer chances than others of choosing schools. According to the Schools Act, guardians' wishes concerning placement in a particular school unit should be met as far as possible. Special school pupils do not, however, have a right to choose schools outside the home local authority if there is no agreement on collaboration between the local authorities. Nor is a local authority obliged to rebuild a school to make it accessible, for example, to a pupil with mobility impairment.

School transport

The right to choose schools is in practice closely connected with the right to school transport. Every local authority is obliged to arrange free school transport for both compulsory school pupils and special school pupils, where this is needed on account of the length of the route, the traffic situation, the pupil's disability or some other specific circumstance (Chapter 6 (6) (3) of the Schools Act and Chapter 4 (7) (1) of the Schools Act). As a reason for the provisions concerning school transport in the Schools Act government bill, it was indicated that a pupil should not have to pay for something in connection with the education in which the pupil is, by virtue of the compulsory schooling, obliged to take part.

Pupils in compulsory schools or pupils in special schools who choose to attend a school other than the one in which the local authority had placed the pupil are not entitled to school transport. This limits freedom of choice for pupils with disabilities. Pupils with disabilities may find it more difficult than others to move between school and the home.

The provisions concerning school transport apply both in special schools and in upper secondary schools. In upper secondary schools and under the Särvox and Komvox schemes, there is no right to free school transport. On the other hand, a

pupil entitled to study help pursuant to the Study Support Act is entitled to compensation for his or her daily travel between the home and school if the route is at least six kilometres (section 2 of the Act 1991:1110 relating to the local authorities' obligation to take care of certain student trips).

The Swedish Disability Federation considers that:

- All pupils should have equal opportunities to choose schools. The responsibility government bill (1990/91:18) laid down a general opportunity for pupils to be able to choose schools. For pupils with disabilities, this has not become reality. The Swedish Disability Federation's experience is that greater freedom of choice for pupils without disabilities in combination with limited freedom of choice for pupils with disabilities leads to increased discrimination. An accessible school is a school in which all pupils can be accepted and none needs to be rejected for being "too expensive". Creating an accessible school must be regarded as an investment that benefits everyone in the school and not as a cost for an individual pupil with a disability.
- Entitlement to school transport should be linked to the pupil's disability and not dependent on which school the pupil attends.

12 Lack of competence on the part of teachers and principals

One in five teachers in compulsory schools and upper secondary schools have not completed teacher training.¹¹³ In local authority schools in 2003, 32 per cent of teachers who had not taken teaching examinations had no more than upper secondary education. The proportion of teachers with college teacher training was in 2003 substantially higher in local authority schools than in independent schools. In independent schools, 35 per cent of compulsory school pupils and half of upper secondary teachers had not completed teacher training. There are also sharp differences between the local authorities in terms of the proportion of teachers with college teacher training. Even if the number of special teachers has risen in the last few years, the local authorities consider that there is still a lack of special teachers working with children in need of special support.

The study shows that only half of the principals have undergone State principal training and that 27 per cent of principals have either participated in State or local authority head teacher training.

The Swedish Disability Federation considers that:

- Teachers and principals must have relevant competence and also be familiar with the laws and statutes that govern pupils' rights to education. Principals must also have special teaching understanding.

¹¹³ For the one I am – on training and intellectual disabilities, the Carlbeck committee, 2003:35, p. 23 *et seq.*

- College training courses for teachers must comprise at least 5 points of disability knowledge. In-service training must be developed for teachers and school personnel who are already professionally active.
- Teacher training courses must comprise teaching of how to train a diversity of pupils and teaching that fits training to pupils with different learning situations.

13 Conclusions and recommendations

The facts presented in this chapter clearly show that Sweden does not meet its commitment under article 13. The fact that a quarter of pupils in compulsory school do not attain the level for a pass in all subjects and also that only two in three pupils have attained basic college competence within four years at upper secondary school shows that there are considerable deficiencies within the Swedish educational system.

The starting point for the recommendations below is General comment no. 13 and UN Standard Rule 6.

The Swedish Disability Federation recommends the Swedish State to:

- Make the following additions to the Schools Act:

Right to action programmes

Pupils who need special support must be entitled to action programmes in compulsory schools, upper secondary schools, special schools and upper secondary special schools.

The right to action programmes, the quality of the investigation and cases where decisions do not coincide with the action programme should be appealed against to the administrative courts.

Right to careers and study guidance

Pupils with disabilities must be given a right to adequate careers and study guidance prior to the selection of upper secondary programmes, placements and higher-level studies.

Right to adapted teaching materials

Pupils with disabilities must, where necessary, be given adapted teaching materials. Determination of the right to adapted teaching materials must be supplemented by accessibility aspects being catered for in all purchases of teaching materials.

to be continued on next page

Right to hearing classes

Pupils who are hard of hearing must be entitled to choose to attend hearing classes.

Right to proper assessment before placement in special schools

Prior to enrolment in special schools, an all-round investigation of each child must be conducted. Interpreters must be used when children do not have Swedish as their mother tongue.

All pupils should be given an opportunity to another investigation in order not to risk being placed in the wrong type of school.

- **Review the provisions of the Schools Act** which mean that independent schools can refuse to take on pupils who need extensive support during their schooling.
- **Review the provisions concerning school transport.** The right to school transport should be linked to the pupil's disability and not be dependent on which school the pupil attends. Pupils with disabilities must have the same opportunities of choosing their schools as other pupils.
- **Endeavour to ensure that training courses for teachers and principals raise competence in relation to disability aspects.** The special teacher function must be safeguarded and the special teachers must be given opportunities for skills development.
- **Endeavour to ensure that adapted teaching materials are produced on a commercial basis.** The State institute given responsibility for teaching materials for students with disabilities may be commissioned to implement Government Bill 1993/94:100. It is stated in this Bill that the group that needs scanned teaching materials is large enough to warrant commercial production.
- **Work to ensure that the college education and in-service training courses for study advisers are given adequate skills in relation to disability aspects.**

Article 15

1 Culture

1.1 Introduction

The starting point for the production of information relating to article 15 has been The Standard Rules description of participation in cultural life. This chapter relating to culture thus deals both with the opportunity for people with disabilities to take part in and the opportunity of themselves engaging in cultural activities. The cultural activities dealt with in this chapter are the activities referred to in General comments number 5, Revised general guidelines regarding the form and contents of reports to be submitted by states parties under articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights: 17/06/91 and in The Standard Rules.

These cultural activities are: "restaurants, hotels, recreation centres and cultural venues" and also "cultural centres, museums, libraries, theatres, cinemas, and in traditional arts and crafts" as well as media.

Under the Convention on the Rights of the Child (article 31 p. 2) and the Convention on the Elimination of All Forms of Discrimination against women (article 13 C), we have also dealt with opportunities for people with disabilities to engage in play and leisure activities.

1.2 Culture for children

In the Save the Children Sweden study "Steps, thresholds and thoughtlessness", some sixty children and young people with functional impairments discussed the treatment and accessibility of places where they like spending their leisure time. This interview-based study showed that:

- half the young people cannot enter the youth centre
- two thirds feel that snack bars and hamburger stands are inaccessible
- more than half the young people consider that going to the cinema does not work well.

The young people consider that accessibility varies widely between different amusement parks and zoos. The large parks, such as Liseberg, Kolmården and Parken Zoo, have been given better reports than the small facilities.

According to the young people themselves, the impediment is chiefly due to ignorance or thoughtlessness on the part of those planning the activities. The children's own advice to politicians is to listen to them.¹¹⁴

¹¹⁴ Steps, thresholds and thoughtlessness – Children and young people with disabilities on the right to play and leisure, Save the Children Sweden, 2002, p. 19; see Annex 1: List of local reports to Save the Children Sweden to the UN Committee on the Rights of the Child.

The description of the situation of disability care issued by the National Board of Health and Housing in 2003 shows that children and young people with disabilities are often dependent on special leisure activities as part of the habilitation process or via a disability organisation. They are often outside the usual leisure range. The National Board of Health and Welfare considers that, to improve the situation, access to leisure aids needs to increase. In addition, the subsidised transport is poorly adapted to young people's needs for flexibility and assistants and companions are needed. Access to facilities (e.g. toilets) and leisure activities is often so poor that children and young people cannot take part despite other requirements being met.

The Swedish Disability Federation would stress that if a child with a disability cannot get to the playground or leisure activities, he/she is deprived of social interaction with children of the same age, which can lead to the child not learning the social skills necessary for development.

Many of the Swedish Disability Federation's member organisations have, in seminars connected with this drafting of this text, described how children cannot acquaint themselves with the range of media available, including children's programmes and films on television, Swedish and non-Swedish films screened at the cinema or available for purchase. For many children with disabilities, it is also difficult to access adapted children's books. The need for books that are easy to read for children and young people with reading and writing difficulties, intellectual disabilities, autism, etc. and books in sign language for children who are deaf and hard of hearing is not met.

Local authority music and the culture school

In 2004, the Swedish Council of Music and Culture Schools (SMOK) conducted an appraisal¹¹⁵ of scope for children and young people with disabilities to take part in the activities of music and culture schools. The appraisal shows that there are major deficiencies within these activities. In 2005, SMOK was granted funds from the Swedish National Council for Cultural Affairs to make the activities available to children and young people with disabilities. The Swedish Disability Federation welcomes SMOK's initiative and hopes that children and young people with disabilities will soon be able to participate under equal terms.

The Swedish Disability Federation considers that:

- What the children and young people say indicates a degree of outsider status that is unacceptable in a society in which we advocate everyone's equal value and right to non-discrimination.
- Children with disabilities must be given an opportunity to take part and express their views when decisions that affect them are taken.

¹¹⁵ Disabilities – Impediment or opportunity in local authority music and culture schools? – An appraisal of opportunities for children and young people with disabilities to take part in the activities of music and culture schools, Stefan Andersson • Dag Krafft, the Swedish Council of Music and Culture Schools, March 2004

- The Swedish Government must develop mechanisms to monitor the delegated responsibility to the local authorities so that every child's right to leisure, play and recreation is met without discrimination.
- The cultural institutions' treatment of children with disabilities must be improved so that all children can benefit from the range of culture on offer. Various information initiatives with a view to raising awareness of the requirements for children with differing disabilities must be taken.
- TV programmes, films and theatre performances must be made accessible to all girls and boys regardless of disability.
- Children's books in an alternative format must be produced on a substantially bigger scale than what is done at the present time.

1.3 Participation of adults in cultural life

The last official statistics concerning cultural habits among people with disabilities were compiled in 1996. Supplementary information on certain groups of people with disabilities was compiled in autumn 2005. A direct comparison can therefore be made for these groups.

Cultural habits 1996

In the study of cultural habits conducted among people with disabilities¹¹⁶ dating from 1996, the Swedish National Council for Cultural Affairs was asked to perform an appraisal and an action programme to promote opportunities for people with disabilities to take part in cultural life. The cultural activities set out in the report are visits to the theatre, concerts, museums, art museums, art exhibitions and libraries, and participation in study circles. Reading habits are also described.

The cultural habits vary between individuals and groups. The study showed that upwards of 70 per cent of the total population between 9 and 79 years of age went to concerts or music events in the course of a year. Nearly as many went to the library. Just over half the population went to the museum, while theatre trips were paid by just under half the population in the course of one year. The statistics for cultural habits among people with disabilities differed markedly from these figures. According to the study, people with mobility impairment were the ones who took part least in culture on offer. As many as 70-80 per cent of those who have mobility impairment never went to a cultural institution. Then came people with visual impairment. This applied to all cultural activities that were investigated.

Library visitors were the ones who went most frequently, which applies also to those with impaired vision, with nearly one quarter visiting the library five times or more over a 12-month period.

¹¹⁶ Access for people with disabilities to culture, Appraisal and action programmes Report from the Swedish National Council for Cultural Affairs 1998:3

Participation in study circles appeared to be largely as appealing to people with disabilities as for the rest of the population, though here, too, people with monility impairment took part to a lesser extent than other groups.

With regard to the reading of books and magazines, people with visual impairment differed markedly from the other groups of people with disabilities. Just over half of the visually impaired never read books and magazines, whereas the reading of weeklies was more common. People with mobility impairment read weeklies to a greater extent than books.

Cultural habits 2005

In the Handu study¹¹⁷ conducted in autumn 2005, the questions were put to people with visual impairment, people who are deaf or hard of hearing and people with mobility impairment. The questions that dealt with participation in cultural life were broadly framed and also covered opportunities of engaging in leisure activities and hobbies.

On the specific question "How do you feel that things work for you when you need to go to the theatre, cinema or lectures/seminars", many answered that they felt excluded from these activities.

- Just over one in five indicated that they do not know how this would work as they do not participate in such activities.
- One third of those who are hard of hearing answered that things work rarely or not at all for those with such activities.
- One fifth of people with visual impairment also felt that it works rarely or not at all for those who go to the cinema, theatre or lectures.¹¹⁸

One form of theatre that nevertheless makes it possible for people who have a command of sign language is "silent theatre". The "Silent Theatre" ensemble is the only professional ensemble in Sweden to produce theatre in sign language. Since 1977, the ensemble has been an independent group within Riksteatern. The repertoire includes not only classical plays but also modern drama and children's plays.

Performance of culture

On the question of "Do you regularly engage in hobby, leisure, club or cultural activities?", a majority of those asked in Handu's study answered that they regularly engage in activities outside the home in their free time. Around a third of all respondents stated that they cannot engage in hobby, leisure, club or cultural activities outside the home to the extent that they would like. No major changes have taken place since 1996, when Handu conducted a similar study.

¹¹⁷ Standard of living study 2005, A report on the standard of living of the mobility impaired, people who are hard of hearing, deaf people and people with visual impairment. The research establishment HANDU AB, 2005

¹¹⁸ Ibid page 62, *et seq.*

According to one report¹¹⁹ from 2005, it is apparent that people with intellectual disabilities engage in more cultural and recreational activities than the rest of the population. Nevertheless, there are very few opportunities for this target group to obtain art training, theatrical training or dance training that might lead to the possibility of being able to pursue this as one's occupation. Society does not give people who have left special schools the chance of attending higher-level art training. The Swedish Association for Persons with Intellectual Disability also feels that the official cultural authorities rarely provide a range of services adapted to this target group. This means that this target group cannot go on cultural events to the same extent as others. This is reinforced by the facts that emerged in the Tideman report in 2000.

Restaurants, hotels and recreation

A major obstacle to visiting restaurants, staying in hotels and participating in recreational activities is that the facilities and places for the activity are often inaccessible, as is the case with, for example, toilets. The Swedish Disability Federation would refer to the introduction to this report and emphasise that the more than 200 notifications received by Swedish Disability Ombudsman in August 2005 clearly show that Swedish society is inaccessible to people with disabilities.

According to a survey conducted by, among others, the Swedish Disability Ombudsman in collaboration with SCB, more than one third of respondents with disabilities state that they have suffered discrimination in restaurants.

Reasons for the low level of participation

It has been claimed that the main reason why people with disabilities do not engage in any hobby, leisure, club or cultural activities is that they do not have the necessary energy. Other reasons are a lack of accessibility and costs that prevent people from taking part in what they want to do. People with mobility impairment state that they find it difficult to engage in general communications, people who are hard of hearing cannot tell what is said because there is often a lack of hearing loops, and deaf people state that there is often a lack of interpreters. On average, one sixth stated that they cannot afford it.

A specific obstacle to many people with disabilities having an opportunity to take part in cultural life is communication with the cultural institutions. The restrictions that have been made in the subsidised transport service with fewer opportunities for each individual user and a greater cost at every opportunity hampers many people's contact with the cultural institutions.

The Swedish Disability Federation considers that:

- Everyone should have an equal right both to engage in and attend cultural activities.

¹¹⁹ Öie Umb-Carlsson, Living Conditions of People with Intellectual Disabilities A study of Health, Housing, Work, Leisure and Social Relations in a Swedish County Population, 2005 Department of Neuroscience, Psychiatry, Ulleråker, University Hospital

- The cultural institutions' attitudes and treatment of people with disabilities must be improved so that everyone can benefit from the range of culture on offer. Various information initiatives with a view to raising awareness of the requirements for children and adults with various disabilities must be implemented.
- People with intellectual disabilities must be given as much chance as others of following higher-level art education courses.
- The State, local authorities and county councils must provide support for cultural players who can provide alternatives and adapted cultural offerings, for example for exhibitions for that are adapted to children and adults with intellectual disabilities.
- The support given by the Ministry of Culture for "Silent Theatre" must remain so that the activity can continue.
- Plans and the provisions of the Building Act that simply remedied obstacles should be eliminated in existing buildings and in general places to which the general public has access must be followed.
- Existing technical solutions (such as hearing loops, subtitling, sign language and visual interpreting) must be used and developed so that films and theatre performances are made available to all people regardless of disability.

1.4 The cultural institutions' accessibility work

Since the previous study by the Swedish National Council for Cultural Affairs concerning cultural habits among people with disabilities was compiled in 1998, a great deal has happened in terms of accessibility. The Swedish National Council for Cultural Affairs conducted a study¹²⁰ in 2005 which shows how the work has progressed.

According to the Swedish National Council for Cultural Affairs analysis of the outside world¹²¹, a positive trend for the cultural institutions can be identified. It is pointed out, however, that accessibility is still generally limited to physical accessibility. The analysis of the outside world shows that most responsible organisations for cultural institutions have some kind of target document for accessibility, but that specific action programmes are lacking for a number of cultural institutions.

During 1998-2004, the Swedish National Council for Cultural Affairs paid about SEK 40 million on 220 projects which are to work on accessibility issues. The contribution has been developed into a tool for the Swedish National Council for Cultural Affairs to perform and speed up the work to achieve the disability policy objectives.

¹²⁰ Obstacles and opportunities for increased accessibility within the sphere of culture, the Swedish National Council for Cultural Affairs analysis of the outside world for disability policy work, 2005

¹²¹ Obstacles and opportunities for increased accessibility within the sphere of culture, the Swedish National Council for Cultural Affairs, 2005

The Swedish Disability Federation considers that:

- We are aware of the major effort that is made so that the range of culture is available to people with disabilities in Sweden. We welcome the individual cultural institutions' accessibility work and also the Swedish National Council for Cultural Affairs action programmes and the accessibility work of individual authorities, particularly the National Property Board.
- The Swedish National Council for Cultural Affairs must impose greater demands on local cultural institutions drafting action plans for greater accessibility.
- To be able to secure a range of culture that is accessible to a variety of people, the cultural institutions must make the most of the knowledge and experience that people with disabilities have. People with disabilities must join in the ongoing work of making the cultural offerings accessible in a more obvious way.
- State contributions for cultural activities must always be conditional on the work being carried out in premises that are accessible. This may mean requirements concerning hearing loops, visual interpretation, automatic door openers and a ban on wall-to-wall carpeting. If the requirements are not met, the State subsidy should be cancelled or reduced.

1.5 Media

An inaccessible media offering

Media such as radio, television, newspapers and the Internet are important channels for keeping oneself informed and participating in what takes place in democratic society. Many people are nowadays prevented from taking part in what is on offer because the content is presented in forms that are not accessible to all. Examples of this are disturbing background noise and a lack of subtitles on the television, which excludes people who are hard of hearing, a lack of sign language interpreting that impedes deaf people and a lack of alternative reading for those with reading and writing difficulties.

Sveriges Television, Sveriges Radio and UR are funded from licensing resources, which all citizens with television receives are required to pay. The responsibility and financing principle, i.e. that the range should be made accessible to all and that this should be done within the limits of the ordinary budget¹²², should therefore apply also to these enterprises.

The media image of people with disabilities

It is a fact that the media in general and public-service enterprises in particular play a crucial role in what is called collective standard formation. In other words, how

¹²² The responsibility and financing principle – every sector in society must be designed and operate so that it is accessible to all citizens. The costs of the necessary adaption measures must be funded within the limits of the ordinary work.

groups and individuals in society are viewed. A doctoral dissertation¹²³ from 2002 examining programmes and features in Swedish public-service television shows that of the total broadcast range, people with disabilities are depicted for less than one per cent of the broadcast time. The way in which people are represented is also monotonous, usually as victims or heroes. The fact that people with disabilities live different lives and have different living conditions virtually always ends up in the background.

A common element can be for people who are exposed to the politicians' cost-cutting measures. In most cases, people are identified by virtue of their disabilities. Where they do not work within the disability movement or at Samhall, they are not given a professional title. Most scripts that the Swedish Disability Federation has investigated as part of a media project deal with people with disabilities as a group without anyone from this group being allowed to participate. In many features, an expert or relative is interviewed who pronounces on people with disabilities without them actually being allowed to speak.¹²⁴

The Swedish Disability Federation's view is that the journalistic way of depicting the deviant and the different has negative consequences for people with disabilities. The people who appear in the media become their disabilities, they become their deviant bodies and incapacities. They are not depicted as ordinary mothers of young children, motorists, tax payers or consumers.

Deficiencies in the make-up of society mean that a disability can arise. To raise awareness that it is society that is disabling and not the individual who is disabled, knowledge of questions relating to people with disabilities must generally increase in society. It is also important that a nuanced image of what it can mean to live with a disability be conveyed.

The Swedish Disability Federation considers that:

- In the agreement between the State and public-service enterprises, requirements must be laid down stipulating that all programmes be made accessible via subtitling, interpreting, reading, etc. Corresponding requirements must be imposed on the commercial channels. In the future broadcasting licences, it must be clearly apparent how the authorities consider that the programme enterprises should approach accessibility issues.
- The State must review its public service agreement with Sveriges television to guarantee a reflection of people with disabilities that does not reinforce stereotypes and attitudes that make it more difficult for people with disabilities to be integrated in society. Models for organised diversity work within public service media exist in the international arena, including the media platform on which the BBC bases its work.

¹²³ Ljuslinder Karin, At close quarters no-one is normal, Disability discourses on Sveriges Television 1956 – 2000, Umea University Library, 2002.

¹²⁴ The media image of people with people with disabilities, the Swedish Disability Federation, 2005

- Clear policies and requirements concerning subcontractors with regard to accessibility and depictions of people with disabilities must be drawn up.

1.6 The information society

In Sweden's present-day information society, access to, for example, the Internet has become increasingly important. Many groups of people with disabilities welcome the opportunities afforded by technology to make the information more accessible. Unfortunately, the use of and the references to information on the Internet mean at the same time that various groups are excluded from the information society. The reason is that the information is not made accessible.

The Swedish Disability Federation considers that:

- The Swedish Government must further contribute to internationally accepted and developed technical standards being followed in both Sweden and in Sweden's collaborating countries.
- We welcome the Swedish Disability Ombudsman's guidelines for an accessible State administration and also the work performed by the Committee for electronic administration and their guidance: Information which, according to the law, must be provided on web sites.
- It is extremely important that information from local authorities, county councils and other public sector players is made available. Ways of achieving this must be developed.

2 Science

2.1 Disability research

As the area of science and research is so broad, the Swedish Disability Federation has chosen in this context only to focus on so-called disability research.

Swedish disability research is currently a major interdisciplinary area of research encompassing research on both the individual's characteristics and society's organisation in relation to people with disabilities. During 2005, the Swedish Disability Federation has appraised¹²⁵ the views of disability research among the organisations that belong to the collaborative body. The results show a large spread in the commitment to research, but that the Swedish Disability Federation lacks influence and participation in how the research is conducted. The Federation wants much greater collaboration and has many proposals in areas in which there is a need for research.

¹²⁵ The disability movement and research – A study of relations based on the disability movement's perspective, the Swedish Disability Federation, 2006

In interviews with representatives of the disability movement with special knowledge of research, dissatisfaction is apparent with the fact that the medical perspective in disability research is too dominant. The research focuses to a large extent on the individual's characteristics and how disabilities should be remedied or compensated. Social research, i.e. how a society interacts with its citizens with disabilities, is more difficult to manage.

As part of the appraisal, it was discussed whether people whom the research concerns should have an active influence in the research process. Nearly all those interviewed agreed that a better dialogue is needed and that the research has much to gain from people's practical experiences and the researchers' specific skills being combined in the research. The appraisal finds that the Government's national action plan for disability policy (Government bill 1999/2000:79), which refers to dialogue and social research, has not been achieved. If anything, the trend since the advent of the research council FAS has been in the opposite direction.

2.2 Disability history – cultural history

The Disability Historical Association is an association that works for the collection, protection and processing of disability policy material and oral sources that elucidate living conditions and society's view of people with disabilities in a historical perspective. Over three years, the association has conducted the disability history centre project. The project has collected source material for future research, organised seminars, issued publications and study material and established contacts with universities and colleges. The project was completed in 2005, but the Swedish Government has not granted the centre a State subsidy so that the work can be made permanent. The centre is now merely living on borrowed time.

The Swedish Disability Federation considers that:

- Disability research must comply with the intentions of the Swedish Government's national action plan for disability policy.
- All disability research must have a gender perspective.
- The Swedish Disability Federation must be allowed to have representatives in the research council and other bodies that decide on research grants and must also be allowed to collaborate in the formulation of the policy documents that concern the research.
- The disability history centre must be given State grants so that the work can continue.

3 Conclusions and recommendations

The information in this chapter clearly shows that people with disabilities cannot take part in cultural life to a very great extent.

Our recommendations below are based on people with disabilities having to have access to the same culture as others, on the basis of their own desires and interests.

The Swedish Disability Federation recommends the Swedish State to:

- Develop mechanisms to follow up the delegated responsibility to the local authorities so that the rights of children and adults to leisure, play and recreation are observed without discrimination.
- Review its agreement with public-service enterprises to ensure that people with disabilities are depicted in a way that does not reinforce stereotypes and prejudices.
- Work to ensure that it is always clear in broadcasting licences for radio and television that programme enterprises must work to bring about full accessibility.
- Ensure that the disability movement's views are always catered for within the bodies that provide research grants and formulate policy documents.

ANNEX 1

Summary of the report

There is a long way to go to achieving participation and equality for people with disabilities

In Sweden, there is unanimous political will to give everyone the opportunities to participate in society. Nevertheless, people with disabilities are discriminated against in relation to all the articles in the Covenant on Economic, Social and Cultural Rights, but with the exception of article 8. Local authority autonomy in Sweden means that responsibility for the practical implementation of many rights covered by the Covenant on Economic, Social and Cultural Rights has been delegated to local authorities and county councils. This report shows that the scope and the level of what support people with disabilities can secure often depends on where in the country one lives. One aspect that is particularly striking is that, in relation to the areas of health, medical treatment, habilitation, rehabilitation support and service, Sweden has very good laws, but they do not function in practice. Despite well formulated laws, people with disabilities do not receive the medical care, the habilitation and rehabilitation or the support and service to which we have a statutory right. The commonest reason is that the united political will does not have an impact in practical implementation – this applies above all in the local authorities. The political rhetoric does not match up with practice, which means that participation and “a society for all” are not achieved for people with disabilities. According to the Standard Rules, medical care, rehabilitation, support and service are absolutely essential for people with disabilities to be able to participate under equal terms.

A lack of knowledge

Another requirement is greater awareness. Here, too, Sweden has a long way to go before people with disabilities can participate in society under equal terms. This report shows that there is a considerable need for more knowledge on the part of, for example, employment agencies, study advisers, teachers, principals and journalists and among those who deal with support and service for people with disabilities. Article 6 makes clear, for example, that only 7 per cent of those with assistance compensation are in gainful employment. For many other groups of people with disabilities, unemployment is over 60 per cent. A major reason for people being excluded from the labour market is negative attitudes on the part of the general public in general and employers in particular.

Media reflect negative attitudes

The media’s representation of people with disabilities also reinforces stereotypes and prejudices. To the extremely small extent to which people with disabilities appear in the mass media, we are often depicted as victims or heroes. It is common for people with disabilities not even to be allowed to express themselves. Others instead talk about the individual. The mass media debate that is conducted can in many respects be characterised as a drive against the “mentally ill”. A simplified image is conveyed to the general public of the mentally ill committing crime and violence after “being released from institutional care” – as described, for example, in Stockholm county council’s official publication entitled The care guide no. 1 2006. This is the case

despite the fact that it is scientifically proven that the mentally ill do not commit violence and crime to any measurable degree more than others.

Lack of accessibility

A lack of accessibility to physical environments, information and communication represents a major impediment to full participation for people with disabilities in relation to all the rights in the Convention. In 2000, a national plan was adopted for disability policy in Sweden for the period 2000 to 2010. Under the plan, public transport must be accessible and simply remedied obstacles in buildings and public places should be eliminated by the year 2010. Nearly six out of ten years of the national action plan for disability policy have now passed. However, not even one quarter of the way has been completed.

Women are particularly vulnerable

The situation for women with disabilities is more disadvantaged in virtually all the articles. Women are, for example, not the object of active initiatives leading to work to the same extent as men. This also means in turn that women have lower incomes, which is often a reason for women feeling to a greater extent that they have poorer health.

Other causes of ill health among both men and women are the experience of discrimination.

Educational opportunities are worse

Education is often crucial to people being able to participate in all areas of society, particularly to get a job and for people to be able to obtain information on their rights. Despite the fact that Sweden has compulsory schooling, Sweden does not have a school for all. Many pupils with disabilities are not given sufficient opportunity to complete their studies with passes at compulsory school and upper secondary level. The poor experiences and the lack of support at school and also the lack of accessibility mean that pupils find it difficult to complete their studies or to engage in higher-level studies.

As a result, the Swedish Government cannot, despite a strong political will, give people the opportunities to participate under equal terms.

ANNEX 2

Summary of the recommendations

In this document, the Swedish Disability Federation has summarised all the recommendations set out in the alternative report. As many recommendations in the report are of the same kind but aimed at different target groups, we have in this document combined recommendations that relate to one another. This is in order to reduce the number of recommendations but also to give the committee a clearer idea of what measures the Swedish Disability Federation considers should be taken by the Swedish Government to improve the situation in Sweden for people with disabilities. The recommendations in this document may therefore often cover a number of areas of rights.

The Swedish Disability Federation recommends the Swedish State to:

Discrimination

- Work to ensure that a lack of accessibility is classed as discrimination.
- Ensure that anti-discrimination clauses are adopted in all public procurement.

Equality

- Ensure that the gender perspective permeates all initiatives by society at all levels of society and in research.
- Set up a committee to investigate the extent to which women and girls with disabilities are discriminated against in relation to men and boys with disabilities. Such an appraisal must be conducted in all areas covered by this Convention. The committee's findings must then form the basis for the implementation of the Convention's rights.

Work

- Commission the State administration to tackle the disability policy target concerning diversity in the employer's role as well.
- Draw up specific proposals for measures that lead to work for young people with disabilities.
- Fight negative attitudes concerning workers with disabilities among labour market participants, within the rights system and in society in other respects by adopting information initiatives that can raise awareness of the support initiatives that society can offer to employers who appoint people with disabilities.

- Ensure that opportunities are created which mean that people with disabilities can obtain placements, within both the public and the private sector.
- Raise the pay contribution level to a level that matches the general increase in pay since the contribution was introduced. The contribution must then be continuously revised upwards so that it tracks the pay trend.
- Abolish Samhall's monopoly and instead implement the model proposed in the report entitled "Not only Samhall".
- Ensure that workers are given the adaptations they need.

Social and economic security

- Ensure that the social security system functions for girls, boys, women and men with disabilities.
- Develop collaboration with the disability movement in all matters concerning the country's social insurance system.

Medicinal care, support, service, habilitation and rehabilitation

- Take steps to ensure that parliamentary decisions, laws and/or central agreements relating to habilitation, rehabilitation, medical care, support and service are in practice followed so that people with disabilities regardless of gender and where one lives are given opportunities to participate under equal terms in society.
- Work to ensure that national guidelines are developed for health care and medical treatment for all diagnosis groups and also ensure the right to care outside one's own county council area in cases where proper competence is lacking within one's own county council area.
- Ensure that the Social Services Act and LSS are observed so that people with disabilities can be given the necessary support and service to participate in society under equal terms.
- Initiate the development of collaborative methods by local authorities, county councils, the social insurance office and labour market participants. Individual action plans concerning the work measures must be continuously drawn up in each individual case so that individuals are given effective care and support efforts. Systems for collaboration must also comprise systems for following up results.
- Ensure that people with disabilities are given access to assistive devices.
- Draw up guidelines to increase accessibility, the environment and service in local residential areas so that people with disabilities can continue living in their homes.

Violence and abuse

- Work to ensure that violence and abuse against children, young people and adults with disabilities are identified and that necessary support can be obtained.

Education

- Review the provisions of the Schools Act so that all people are given equal opportunities of adequate education.
- Review the provisions relating to school transport so that pupils with disabilities are given the same opportunities to choose schools as other pupils.
- Work to ensure that college education and in-service training courses for teachers, principals and study advisers provide proper competence in matters relating to disabilities.

Culture and science

- Develop mechanisms to follow up the delegated responsibility to the local authorities so that the rights of children and adults to leisure, play and recreation are observed without discrimination.
- Review one's agreement with public-service enterprises in order to ensure that people with disabilities are depicted in a manner that does not reinforce stereotypes and prejudices.
- Work to ensure that it is always apparent in broadcasting licences for radio and television that the programme enterprises must strive for full accessibility.
- Ensure that the disability movement's views are catered for by the bodies that provide research grants and draw up policy documents.

General recommendations

- Initiate extensive programmes for raising competence for key individuals such as study guides, employment services, teachers, journalists and social services personnel.
- Reinforce user input by drawing up guidelines and approaches for effective user input at all levels of society.

ANNEX 3

Organisations of people with disabilities that support the report

Swedish Aphasia Association.

Swedish Asthma and Allergy Association.

Bloodcancer Association.

The Swedish Breast Cancer Association.

The Swedish National Association for Deaf, Hearing impaired and Language impaired Children.

Swedish Federation of People With Mobility Impairments.

The Swedish Association for the ElectroSensitive.

Swedish Hemophilia Society.

The Swedish Association for Persons with Difficulties in Reading and Writing/Dyslexia.

The Association of the Swedish Deafblind.

Swedish National Society for Persons with Intellectual Disability.

The Swedish Heart - Children´s Association.

The Swedish Heart- and Lung Association.

The Swedish Association of Hard of Hearing People.

ILCO-Sweden Ostomy Association.

The Swedish Association of Persons with Neurologically Disabilities.

Swedish OCD foundation Ananke.

Primary Immunodeficiency Organization.

Swedish Psoriasis Association.

The Swedish National Association for Disabled Children and Young People.

The Swedish Rheumatism Association.
Swedish Fibromyalgia Association.
The Swedish National Association Attention.
The National Autistic Society of Sweden.
The Swedish Cystic Fibrosis Association.
The Swedish Association for HIV Positive People.
Swedish Association of Brain Injured and Families.
Swedish Association of People with Stomach and Bowel Diseases.
The Swedish Association for Kidney Patients.
The National Organisation of Cancer of the Prostate.
The Swedish National Association for Social and Mental Health.
The Swedish Association of Survivors of Traffic Accidents and Polio.
The Swedish Coelic Society.
The Swedish Diabetes Association.
Swedish National Association of the Deaf.
The Swedish Epilepsy Association.
The Swedish Association of Laryngectomees.
Swedish Stuttering Association.
Swedish Schizophrenia Fellowship.
The Swedish Stroke Association.
The Swedish Parkinson's Disease Association.
The Swedish Association of Rare Disorders.
Swedish Association of Dental Mercury Patients.

Diabetes Youth Association in Sweden

Swedish Young Psoriasis Association

The Swedish Organisation for Hard of Hearing Young People

Swedish Association of Visually Impaired Youth

The Swedish Cochlearimplant Children Society

Swedish Parent Association for Dyslexic Children

The Swedish Thalidomide Society, NGO

The Swedish Ichthyosis Association

The Swedish Migraine Association

The Swedish Association of the Visually Impaired

The Association of Finish Speaking Visually Impaired in Sweden

The Association of Late-Deafened in Sweden

The Swedish Obesitas National Association

Forum – Women and Disability in Sweden

ANNEX 4

List of abbreviations:

ADHD	Attention Deficit/Hyperactivity Disorder
DAMP	Deficits in Attention, Motor control and Perception
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
DHR	Swedish Federation of People with Mobility Impairments
FAS	Swedish Council for Working Life and Social Research
FUB	Swedish National Society for Persons with Intellectual Disability
Handisam	The authority for disability policy co-ordination
HANDU	The research establishment HANDU
HIV	Human Immunodeficiency Virus
HRF	The Swedish Association of Hard of Hearing People
HSL	Healthcare and Medical Treatment Act
IFAU	The Institute for labour market policy evaluation
Komvux	Education for adults with developmental disorders
LASS	Act on Assistance Compensation
LSS	Act on support and service for certain individuals with disabilities
SCB	Statistics Sweden
SDO	Swedish Disability Ombudsman
SFS	Swedish Code of Statutes
SISUS	National Agency for Special Educational support
SMOK	The Swedish Council of Music and Cultural Schools
SoL	Social Services Act
SOU	The Assistive Devices Report
The Standard Rules	UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities
Särvux	Specific form of school aimed at adults with intellectual disabilities