



Report on the social inclusion and social protection of disabled people in European countries

Country: Sweden
Author(s): Berth Danermark & Jamie Bolling

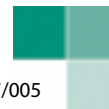
Background:

The [Academic Network of European Disability experts](#) (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its Disability Policy Unit. In particular, the activities of the Network will support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.

This country report has been prepared as input for the *Thematic report on the implementation of EU Social Inclusion and Social Protection Strategies in European countries with reference to equality for disabled people*.

The purpose of the report ([Terms of Reference](#)) is to review national implementation of the open method of coordination in social inclusion and social protection, and in particular the National Strategic Reports of Member States from a disability equality perspective, and to provide the Commission with useful evidence in supporting disability policy mainstreaming.

The first version of the report was published in 2008. This is the second version of the report updated with information available up to November 2009.



Summary of changes since 2008

Housing and homelessness:

No new data on homelessness are available. In 2005 in total 17 800 persons were reported homeless of which about 75% were men. 12% lived in various kinds of emergency housing. 40% of the homeless had a psychiatric disorder.

New strategies and actions for the inclusion of disabled people:

The Human rights for persons with disabilities has been approved by the parliament and on 15 December 2008 the government decided to ratify the UN convention. Furthermore the Government has decided to sign the Optional Protocol. Both came into effect on 14 January 2009. A Delegation (Delegation for Human Rights in Sweden) has recently proposed allocation of a number of tasks related to promoting, protecting and monitoring to the Equality Ombudsman.

New changes in incomes, benefits and pensions:

Disabled people receive ten types of services specified by the Act concerning Support and Service for Persons with Certain Functional Impairments ("LSS", 1993:387). Municipalities reported that on the 1 October 2008 just over 58,700 individuals received one or more LSS services, excluding counselling and other personal support. This is about 1,900 more compared with 2007, or an increase of about 3 percent. County councils and municipalities responsible for counselling and other personal support reported that on the 1 October 2008 roughly 6,700 individuals had been granted counselling and other personal support in accordance with LSS. This is a decrease of about 22 percent compared with 2007.

No data on changes in incomes for disabled people are available. No changes in the pension system have been implemented.

New changes in long-term care and support:

A new act on free choice systems (2008:962) has been implemented. The act is intended to function as a voluntary tool for municipalities and county councils that want to provide in-house services with competition, so as to be able to transfer the choice of provider to the user. The act has been criticised by disability associations, which strongly oppose the possibility that support to disabled people might be transferred from the public sector to profit driven organisations.

Implications of the economic crisis:

More restrictive applications of services specified by the Act concerning Support and Service for Persons with Certain Functional Impairments have been reported ("LSS", 1993:387).



PART ONE: SOCIAL INCLUSION PLANS (GENERAL)

1.1 Published plans for social inclusion and protection

The most important document of the last decade concerning disability policies is *From patient to citizen: a national action plan for disability policy* (Government Bill 1999/2000:79¹) which was passed by the Parliament on 31 May 2000. According to the Bill, the objectives of disability policy are:

- a society based on diversity;
- a society designed to allow people with impairments of all ages full participation in the life of the community;
- equal opportunities in life for girls and boys and women and men with impairments.

Work within disability policy should focus on three tasks in particular:

- identifying and removing obstacles to full participation in society for people with impairments;
- preventing and fighting discrimination against people with impairments;
- making it possible for children, young people and adults with impairments to live independent lives and to make their own decisions about their own lives.

The underpinning ideology is that people with impairments must not be the objects of special measures but regarded as citizens with the same rights and opportunities as others. There has been a clear shift of focus from the individual to society, as expressed in the title of the Bill. This view of disabled people as citizens requires that all policy areas should take disability into account.

The plan does not contain any concrete legal proposals. Furthermore, it does not discuss sanctions for those who do not comply with, for example, accessibility requirements. Although the national plan addresses structural issues from an ideological point of view, it does not set out how the plan is to be implemented and how this would affect the structures that marginalise people with impairments.

1.2 Major actions

The UN Human Rights Council resolution *Human rights for persons with disabilities* was approved by the Parliament and, on 15 December 2008, the government decided to ratify the UN Convention. Furthermore, the government signed the Optional Protocol. Both came into effect on 14 January 2009. A delegation (the Delegation for Human Rights in Sweden) has recently proposed that the Equality Ombudsman be allocated a number of tasks related to promoting, protecting and monitoring the rights enshrined in the Convention.

The Equality Ombudsman (DO) is a government agency that works to combat discrimination and to promote equal rights and opportunities for everyone. The Equality Ombudsman was formed on 1 January 2009 when the four previous anti-discrimination ombudsmen were merged into a new body. The previous authorities were the Equal Opportunities Ombudsman (JämO), the Ombudsman against Ethnic Discrimination (DO), the Disability Ombudsman (HO) and Ombudsman against Discrimination on grounds of Sexual Orientation (HomO).

This means that a person can now turn to a single authority regardless of the reason why (s)he has faced discrimination. (S)he may also have been discriminated against for several reasons, for example because she is a woman from Iraq with a hearing disability, or because he is a young homosexual man with dyslexia.

¹ <http://www.regeringen.se/sb/d/108/a/833>



On 1 January 2009 a new comprehensive [Discrimination Act](#), which covers more areas than before, came into force. The Discrimination Act prohibits discrimination on grounds of sex, transgender identity or expression, ethnicity, religion or other belief, disability, sexual orientation or age.

The main task for the DO is to ensure that anti-discrimination legislation is followed. The DO also supervises how employers, universities and schools live up to the anti-discrimination legislation's demands for measures to prevent discrimination. The Equality Ombudsman does this mostly by reviewing gender equality plans and equal treatment plans. The Equality Ombudsman's duties also include raising awareness and disseminating knowledge and information about discrimination and anti-discrimination legislation.

Anti-discrimination acts

[Discrimination Act](#) (2008:567)

[Act on the prohibition of discrimination in working life against people with disabilities](#) (1999:132)

[Equal Treatment of Students at Universities Act](#) (2001:1286)

[Act on the prohibition of discrimination and other degrading treatment of children and pupils](#) (2005/06:38)

The Disability Ombudsman (before 1 January 2009) repeatedly pointed out to the government that despite the national plan *From patient to citizen: a national action plan for disability policy* and in spite of a number of laws, the level of welfare among people with impairments is still far below that of the general population. With the exception of the group of people receiving services based on the Act on Support and Services for People with Certain Functional Impairments (see below), the situation is more or less the same now as it was three to four decades ago. The Disability Ombudsman's explanation for this state of affairs is that reforms in the field have been oriented towards the individual and not towards structural societal factors.

[Act \(1993:387\) on Support and Services for Persons with Certain Functional Impairments](#)

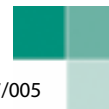
This act includes ten measures for increasing the welfare of some people with impairments (see also 4.2 below). One of the most important measures is the right to personal assistance if the person fulfils the set criteria. This has resulted in about 11,000 people with severe impairments obtaining personal assistance, which has significantly improved their welfare and ability to live independently. Another measure is that some people with impairments are entitled to 'daily activities' (i.e. activities organised in a day centre, through a cooperative or other organisation). This measure benefits the highest number of individuals with about 25,800 receiving the entitlement in 2006. However, there are reports of this service's low quality. The most important issue is that the service tends to trap recipients instead of helping them establish themselves on the regular employment market - most have not yet made the transition from daily activity to employment. After an investigation in 2008, the National Board of Health and Welfare stated that one of the obstacles is that labour market partners do not regard this group as part of their target group. Another obstacle is the lack of co-operation between public and private actors in the field.

A new act on free choice systems (2008:962) has been implemented. The act gives municipalities and county councils the option of allowing other organisations to offer services that compete with their own, so as to transfer the choice of provider to the user. The act has been criticised by disability associations, which strongly oppose the possible transfer of support to disabled people from the public sector to profit-driven organisations.

Public authorities' accessibility

All Swedish government authorities are responsible for ensuring that their premises, activities and information are accessible to people with impairments. The Disability Ombudsman has developed guidelines and as of 2005 Handisam, the Swedish Agency for Disability Policy Coordination, has been responsible for their implementation².

² <http://www.handisam.se/upload/English/Riv%20Hindren%20English.doc>



Involvement of people with impairments and their organisations

People with impairments are actively represented on issues of inclusion through their disability organisations. Disability organisations have a central role in following up and reporting on the situation of people with impairments. Organisations also contribute to achieving policy goals relating to increasing awareness of issues. Organisations are also key players in the consultation process when bills or proposals are to be passed. A disability delegation was established in 2007. This body is an important forum for negotiation and a channel for information between the government and disability organisations. The Minister for Elderly Care and Public Health is the chair of the delegation. There are fourteen members from disability organisations, and the state secretaries of several ministries, including the Ministry of Finance and Ministry of Environment, are members.

1.3 Recent research on disabled people's equality and social inclusion

Evaluations of Swedish disability research indicate that an individual perspective dominates research, and that research focusing on equality and social inclusion from a societal perspective is not prominent (see for example the Swedish Council for Working Life and Social Research (2001)).

However, there have been some important contributions over the last two years which address equality and social inclusion. Below is a summary of some of these:

Jerlinder *et al.* (2008, 2009) address the issue of social inclusion in education in the context of physical education (PE) for pupils with physical impairments within the compulsory school system. The authors highlight that justice in education for pupils with impairments creates certain dilemmas. A 'school for all' means that educators are faced with the dilemma of impairment being considered unimportant, when in fact it seems to matter very much. Jerlinder *et al.* explore ways out of this general educational dilemma through justice theories of resource distribution and culture. The philosopher Nancy Fraser's notion of 'social status', together with a pluralistic approach to identities where personal experiences are given a place, is used to propose a solution to the dilemma. It is concluded that redistribution of economic resources and social recognition are necessary if social justice within PE is to become a reality.

In a study comparing 2,144 people born between 1941 and 1980 who attended a special education programme for the deaf with 100,000 randomly chosen individuals from the total population born between 1941 and 1980, Rydberg *et al.* (2009) show that the deaf population has a lower level of educational attainment than the general population. Women have a higher level of educational attainment than men, and younger people have a higher level than older people in each population. Neither sex, age category, nor immigrant background accounts for the variance in the level of educational attainment between the populations. Educational reforms have not been sufficient to reduce the unequal level of educational attainment between deaf and hearing people.

Over the last 10 years there has been an increase of about 100% of pupils enrolling in special schools for people with intellectual impairments, despite an official emphasis on a 'school for all' and on inclusion. Tideman (2007) has investigated the mechanisms behind this increase. He stresses that an important explanation is the financial cutbacks to public schools over the last decade. When there is a struggle over resources, there is a need to categorise and label pupils to obtain adequate resources. He concludes that despite the rhetoric of inclusion, there is in practice a process of exclusion in the Swedish educational system.

In an in-depth interview study, Strandberg (2009) investigated the adaption process experienced by individuals who as adults acquired a traumatic brain injury (TBI). The aim of the study was to increase the knowledge and understanding of this process, and to describe the impact of support in everyday life, with a focus on social recognition. The central construction of 'recognition' was analysed from three different dimensions: the individual dimension, the legal dimension, and the value dimension.



An important finding was that a majority of the informants were satisfied with support from society, such as hospital care, rehabilitation and community support. Such support initially proceeded without problems but as time passed, the responsibility for arranging longer-term services shifted to the person with TBI. Long-term support addressing physical, cognitive as well as psychosocial consequences of TBI is important for outcomes. It is also important to note that the majority of the informants had great difficulties in returning to working life after injury. Many of the informants reported negative experiences regarding social recognition.

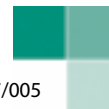
The social inclusion of people with deaf-blindness was studied by Möller (2008, 2009). In her study, Möller reports the misrecognition and extreme vulnerability of this group. Restrictions on their participation in society are far-reaching. Services may present systematic barriers or are sometimes missing.

Researchers at the Centre for Ageing and Supportive Environment³ have published a unique list of obstacles to accessibility in the built environment (Carlsson *et al.*, 2008).

In 2005 a total of 17,800 people were reported homeless, of whom about 75% were men. 12% lived in various kinds of emergency housing. 40% of the homeless had a psychiatric disorder.

In Request 2 - *Disability and employment*, a summary can be found of research focusing on inclusion and the labour market.

³ see <http://www.med.lu.se/case>



PART TWO: INCOMES, PENSIONS AND BENEFITS

2.1 Research publications (key points)

In 2002 an evaluation of the development of welfare for people with impairments was published (See Ds 2002:32⁴). The authors of the report conclude that 'people with disabilities are at a disadvantage with regard to many aspects of welfare...', and that divisions have not changed over the past ten years. Using a broad definition (people with at least one of the following: impaired sight, impaired hearing, impaired mobility and long-standing mental health problems), the number of people was about 13% of the Swedish population, or 700,000 people in all. People with hearing impairments and mental health problems increased substantially over the period. People with impairments had poorer health than others of the same age group and the authors stressed that 'the difference is substantial even where there is no particular reason to expect an association between the disability and the health indicator in question'. Although levels of education improved among the group, 'they were still far more likely than the rest of the population to have only a basic education'. The levels of gainful employment were lower and this could not be explained entirely by ability to work. However, it could be noted that disposable income did not differ noticeably from that of other people even though they experienced greater day-to-day economic difficulties than the population in general owing to expenditure on medical care, drugs, transport etc. The group was also more dependent on daily help than other people. From a gender perspective, the report shows that differences between men and women are about the same as in the general population in terms of welfare, i.e. women are consistently disadvantaged. Women with impairments are in particular at a greater risk of violence than men with impairments.

Lewin *et al.* (2008) have evaluated some aspects of the Swedish Disability Act (the LSS), which was introduced to guarantee good living conditions for people with severe disabilities. A specific goal was to overcome local variation in support. However, considerable differences still remain between municipalities. In the study, the authors identified six characteristics that explain this variation: earlier presence of residential institutions, population density, human capital (age, education, employment, and health), local culture, geographic area and stable left-wing government. The results support a need-responsiveness model of welfare support but also signal accessibility problems and a regional propensity to demand and supply independently of need. This means that spatial equity is violated. In sum, it still matters where you live.

There is a worrying lack of accurate data concerning developments over recent years. However, there are no indications that the differences between people with impairments and the general population described above have changed. On the contrary, the investigation by the Swedish National Institute of Public Health described below (see 3.1) suggests otherwise.

2.2 Type and level of benefits (key points and examples)

A person with impairments in Sweden is entitled to various types of services, which are allocated according to need. The different types of services are regulated by law and have their origins in the disability investigation of 1965. People with impairments apply for services through the municipality in which they live. Services can be financial or practical. There is support for travel, study, work, and recreation. Support varies from access to information and personal assistance to special housing. Below is a short description of the most important benefits for people with impairments and the laws that regulate services:

⁴ <http://www.regeringen.se/sb/d/108/a/885>

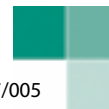


Table 1 - Social Benefits

Social benefit, number of recipients and changes from 2007(%)	Description of benefit	Regulating legal document
Car allowance 2,170; (-20%)	<p>An allowance to help buy a vehicle or other means of transport such as a moped or motorcycle for people with a permanent impairment who have problems using public transport. Parents of children with impairments may be entitled to a car allowance if they need support to travel with their child.</p> <p>The basic car allowance is: 60,000 SEK for buying a car 12,000 SEK for a motorcycle 3,000 SEK for a moped.</p> <p>For people on a low income, there is a complementary grant based on income of a maximum amount of 40,000 SEK.</p> <p>Adaptations to the vehicles are covered on top of these grants.</p>	The law regulating this service is Ordinance (1988:890) on car allowances for people with disabilities.
Sickness benefit Activity support	<p>A person is entitled to sickness benefits (for people aged 30-64 years) or activity support (for people aged 19-29 years) if their working capacity is reduced by at least one-quarter. This measure has replaced the early retirement pension.</p> <p>Activity support is paid daily, and the rate is 223 SEK per day if the person does not fulfil the requirements for unemployment. If these requirements are met, the amount is between 320 SEK and 680 SEK per day. The maximum is 196,800 SEK/year.</p>	These entitlements are regulated by the (1962:38) Social Insurance Act.
Disability allowance 61,385; (0%)	<p>An allowance to cover substantial extra costs in day-to-day living as a result of impairments.</p> <p>Disability allowance can be 36%, 53% or 69 % of an amount set annually by the government, which varies from one year to the next. The rate paid depends on the need for help and extra costs.</p> <p>Disability allowance in 2008: 36 %: 14,760 SEK 53 %: 21,730 SEK 69 %: 28,290 SEK</p>	The law regulating this service is the (1998:703) Act on disability allowance and care assistance.

Assistance Benefits ⁵ 15,293; (+7%)	<p>People who need personal assistance in their daily lives for more than 20 hours a week have the right to assistance benefits to pay for personal assistants.</p> <p>Assistance benefits are based on the number of hours negotiated, and the amount per hour is 237 SEK for 2008.</p>	The right to personal assistance is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments and (1993:389) Assistance Benefit Act.
Wage subsidy (total during 2008) 71,073; (-9%)	<p>Grants to employers for employing people with work-related impairments. The aim of this social support is to help people with work-related impairments obtain and keep a job that they would otherwise not have.</p> <p>Wage subsidies are paid to the employer for gross salary costs up to a salary of 16,700 SEK per month.</p>	The wage subsidy is regulated by the (2000:630) Ordinance on certain support for persons with work-related impairments.
Public protected employment (total during 2008) 6,303; (-10%)	<p>Public protected employment is provided for people with impairments who have a reduced working capacity. This employment measure includes elements of rehabilitation. The employment should lead to work in the normal employment market.</p> <p>Salary is to be paid based on the type of job and the capacity to work.</p>	Public protected employment is regulated by the (SFS 2000:630) Ordinance on special measures for persons with impairments with reduced working capacity and (SFS 2000:628) Ordinance on labour market activity.
Sheltered employment 21,200; (0%)	<p>Sheltered employment is organised through the state-owned company Samhall AB. Employment is offered to people with impairments who have a reduced working capacity.</p> <p>A salary is paid according to a collective or union agreement.</p>	Sheltered employment is regulated by the (SFS 2000:630) Ordinance on special measures for persons with impairments with reduced working capacity and (SFS 2000:628) Ordinance on the labour market activity
Special housing 22,323; (+3%)	Special housing or other specially adapted homes for adults with impairments.	The right to supported housing is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.
Allowances for housing adaptation 75,000; (+3%)	<p>Grants for necessary changes to housing to allow a person with impairments to live an independent life in his/her own home.</p> <p>Amounts of grants vary depending on the adaptations needed. Grants for elevators are rare and considered extreme exceptions. Court cases may arise when this need is disputed.</p>	The entitlement is regulated by the (1992:1574) Act on Grants for Housing Adaptation.

⁵ Note that Assistance Benefits and Personal Assistance (see Table 2) are the same type of support but with different names, and different authorities are responsible.

Parental benefits 2007: 43,000 No data for 2008	Parental benefits are paid to parents for children who are sick or have impairments. The benefit is to cover extra costs and to be an economic support for parents who cannot work full time because of their children's care needs. Parental benefits are based on price-indexed amounts, and are 25%, 50%, 75% or 100%. For 2008: 100% benefit: 8,542 SEK per month; 102,500 per year. 75% benefit: 6,404 SEK per month; 76,875 per year. 50% benefit: 4,271 SEK per month; 51,250 per year. 25% benefit: 2,135 SEK per month; 25,625 per year.	
Allowances to family members 2007:1,200. No data for 2008	Allowances to family members are grants provided by the municipality and are used to encourage kin to provide supervision or care to people with impairments. The amount given per month varies from one municipality to another. A 2008 example from Ale municipality is the monthly amount of 1,500 SEK.	This entitlement is regulated by the (1962:38) Social Insurance Act.

1) Came into practice 2003

2.3 Policy and practice (summary)

There are a number of policy documents and laws aiming to protect and increase the inclusion of people with impairments in society (see above). Research in the field shows great inequalities between people with impairments and the general population.

Disability research in Sweden is very oriented towards individuals. A review of Swedish disability research suggests that disability research in Sweden should utilise official statistics for in-depth analysis of the status of people with impairments. Furthermore, despite the fact that the inequalities seem to be constant over the last decades, the welfare of people with impairments is not an important political issue. When addressed, it most often concerns individual compensatory measures whereas there is a need to address more structural factors.

Swedish pensions for people with impairments are referred to activity support or sickness benefits, and are often used as an excuse to not give adequate support to people with impairments to obtain gainful employment or participate in other meaningful activities.

The government has recently investigated the increased cost of supporting people with impairments, including pensions (mainly related to measures specified by the Act on Support and Services for Persons with Certain Functional Impairments, see below), and is looking for ways to address the issue. At the moment the outcome of this process is not known, but more restrictive access to services specified by the Act on Support and Services for Persons with Certain Functional Impairments has been reported (LSS, 1993:387).



PART THREE: CARE AND SUPPORT

3.1 Recent research publications (key points)

The majority of studies related to the needs of individuals with psychiatric disabilities focus on their contact with, and use of, the traditional mental health system (see for example, Yilmaz *et al.* 2009; Hillberg *et al.* 2009ab). However, conceptions of disability that take the environment into account have only shown limited success in expanding the views of the psychiatric community to include social and organisational contexts. Rosenberg *et al.* (2008) carried out inventories of need for people with psychiatric disabilities (a legal responsibility of the social service system in Sweden) for three municipalities. Results indicated that these individuals defy psychiatrically defined categories and seek support in the community based on their own experience of need.

On 1 October 2008 the following statistics were available regarding people with impairments:

Municipalities reported that on 1 October 2008 just over 58,700 individuals were receiving one or more LSS services, excluding counselling and other personal support. This is approximately 1,900 more compared with 2007, or an increase of about three per cent.

County councils and municipalities responsible for counselling and other types of personal support reported that on 1 October 2008 roughly 6,700 individuals had been granted counselling and other personal support in accordance with the LSS. This is a decrease of about 22 per cent compared with 2007.

The total number of LSS services delivered was roughly 109,000. Approximately 87 per cent of these services involved people with learning difficulties or autism, or a condition resembling autism. Most of those involved – just over 28,000 individuals – received daily activities through the LSS. Approximately 22,300 resided in special homes for adults with disabilities or other specially adapted homes for adults; about 18,400 were provided with a contact person; just over 10,200 had short stays away from home arranged; just under 9,700 had assigned companions; roughly 6,700 received counselling and other types of personal support; and just under 5,200 received short-term supervision. Other LSS services provided were for fewer than 5,000 people in each of the service categories.

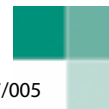
About 50 per cent of the approximately 1,400 children and young people who resided in their family home or special housing for children and young people lived in a municipality other than the one that paid for the service. About 10 per cent of the children and young people stayed in their family home, and the remaining 90 per cent in special housing.

People entitled to personal assistance under the LSS were most frequently granted 16-20 hours per week. Just over 700 of the 3,500 people receiving personal assistance under the LSS were provided with 16-20 hours of assistance per week (the National Board of Health and Welfare, 2009).

According to statistical data submitted by municipalities, roughly 21,800 people in the age group 0-64 at some point received health and medical care under the responsibility of the municipality in accordance with Chapter 18 of the Health and Medical Services Act. Approximately half of these people were women and half were men.

According to a public investigation⁶ the total cost for care and support provided under the Act on Support and Services for Persons with Certain Functional Impairments was 41.9 billion SEK (4.3 billion EUR) in 2006. Over the period 2000-2006 the cost of support increased by 143% to the state and by 58% to municipalities. However, the cost per activity was constant over the period and the increase in costs is related to an increase in the number of people with impairments requiring care and support: an increase of 20%.

⁶ see <http://www.regeringen.se/sb/d/10057/a/109952>, in Swedish



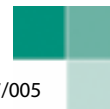
The Swedish National Institute of Public Health conducts an investigation into the health status of people with impairments every two years. The latest report (http://www.fhi.se/PageFiles/3404/R200817_Halsa_pa_lika_villkor0807.pdf) concluded that approximately 1.5 million people aged 16 to 84 years (about 17% of the population) had one or more impairments. Poor health was 10 times more common among those with impairments than among the general population. Illness was more frequent among those with a motor impairment (43% of men and 32% of women reported a poor general state of health). In many cases illness was directly related to impairments, but a large proportion of illness related to financial insecurity, discrimination and lack of access: factors closely linked to disability. Among other important findings were that people with impairments, to a larger extent than the rest of the population, had little faith in social institutions and lacked emotional and practical support. Their social participation was also significantly lower than for the general population.

3.2 Types of care and support (key points and examples)

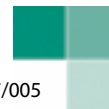
The following table summarises the types of care and support for people with impairments provided by the main authorities in Sweden.

Table 2 – Care and Support

Practical services Number of recipients and changes from 2007 (%)	Description of care/support	Regulating legal document
Home respite service 3,349; (-4%)	Temporary assistance in the home for a person with impairments, to provide respite for relatives caring for the individual. Home respite is a right under the 1993:387 Act. These services are, in principle, free of charge. Costs, such as food and transport, vary from county to county.	The right to respite in the home is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.
Daily activities 28,079; (+9%)	This refers to all activities organised in a day centre, through a cooperative or other organisation. The amount paid to the user participating in daily activities varies between counties.	The right to daily activities is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.
Special transport service 2007: 69,000	Special transport for people with impairments who cannot use public transport. The cost varies from one municipality to another. Using Stockholm as an example, one trip by taxi or bus will cost 70 SEK per 30 kilometres of the trip. The maximum cost per month is equivalent to the price paid by the general public for a monthly travel card for the public transport system, which is 690 SEK.	Entitlement is regulated by the (1997:736) Special Transport Services Act.



Legal guardian	<p>A legal guardian for an individual with impairments who at the age of 18 cannot take care of his own legal affairs.</p> <p>Costs for legal guardians vary between counties, both in terms of the cost to the user and the fee paid to the legal guardian. The user is responsible for the cost.</p>	The legal guardian service is regulated by the Parental Code, Chapter 11, 4§.
Home help 2007: 19,100	<p>Help in the home to clean, wash, do shopping, cook, or assist with personal care to eat, dress, move, attend to personal hygiene, or provide another service to prevent isolation.</p> <p>The cost for this service varies between municipalities, both in terms of the cost to the user and the salary paid to people providing home help.</p>	Home help is regulated by the (2001:453) Social Services Act.
Technical aids	<p>Technical aids are provided through county councils or through the municipalities for those with impairments.</p> <p>The cost of technical aids varies between counties. Some counties provide all equipment free of charge while others charge minimal fees.</p>	The Health and Medical Services Act (1982:763) regulates the provision of equipment.
Contact person 18,423; (+5%)	<p>A person who facilitates life for a person with impairments, making it possible for the person to live independently and not in isolation.</p> <p>Contact persons are in principle free of charge.</p>	The right to a contact person is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.
Short-term stays away from home 10,230; (-3%)	<p>Places are provided to give people with impairments a change of environment and access to recreation. The service can increase a child's independence.</p> <p>Short-term stays are in principle free of charge.</p>	The right to short-term stays away from home is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.
Companion service 9,656; (0%)	<p>A personal service adapted to the needs of individuals with impairments enabling them to take part in activities outside the home and to live a good life. The service can be used to participate in cultural activities, sports, or to take a vacation.</p> <p>Companions are in principle free of charge.</p>	The right to a companion service is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.

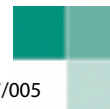


<p>Personal assistance⁷ 3,501; (-5%)</p>	<p>Personal assistance is available to those with certain functional impairments needing assistance to eat, communicate, to dress, with personal hygiene, and to come out of the home enabling the person to live an independent life. It is support to manage personal needs and to enable the service user to fully participate in society.</p> <p>Assistance benefits are based on the number of hours negotiated and the amount per hour is 237 SEK for 2008. Salaries paid by the municipalities vary. Municipalities are responsible for the first 20 hours of assistance.</p>	<p>The right to personal assistance is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.</p>
<p>Personal ombud 2007: 6,000</p>	<p>A person assisting people with psychological impairments; a resource to ensure that the individual's needs are met. The decision was taken by the government in 2000 to give national grants to municipalities to run this service.</p> <p>The amount charged for the service of a personal ombud varies from county to county as do the salaries paid to personal ombuds.</p>	<p>The National Health Board is responsible for co-ordinating this service.</p>
<p>Counselling and other personal support 6,662; (-30%)</p>	<p>An entitlement for a person to extra support and advice from a person with extensive knowledge and experience of living with severe functional impairments. This can be a social worker, psychologist, physiotherapist, pre-school counsellor, dietician etc.</p> <p>Counselling and support are in principle free of charge.</p>	<p>This right is regulated by the (1993:387) Act on Support and Services for Persons with Certain Functional Impairments.</p>
<p>Interpretation service (for people with hearing impairments)</p>	<p>Entitlement to interpretation in daily life for doctor's appointments, contact with authorities, errands or hobbies.</p> <p>Charges for this service vary between counties.</p>	<p>Rules regulating the interpretation service are set out in the Health and Medical Services Act (1982:763)</p>

There are also different forms of care, e.g. municipality home care, short-term care, elective institutional care, and in 2006 there were 16,570 decisions to provide such care (note that each person can receive more than one type of care).

Municipalities also provide people with impairments with different forms of residential support, such as residential housing for children and adults. In 2006 there were about 28,100 individuals living in residential housing, an increase of about 20% since 2000.

⁷ Note that Personal Assistance and Assistance Benefits (see Table 1) are the same type of support but with different names, and different authorities are responsible.



PART FOUR: SUMMARY INFORMATION

4.1 Conclusions and recommendations (summary)

National policy expressed in the national plan emphasises that disability should be an integral part of all activities in society. The ideology of inclusion is very evident in a number of policy documents. A number of important acts further underline this focus on disability. Laws that guarantee people with impairments benefits, care and support according to their needs are put into practice. Laws protecting people with impairments from discrimination are also important measures encouraging inclusion. However, despite these theoretically forceful measures, there are a number of indications that the situation is either not improving or worsening in some important aspects. In education, a number of indicators indicate growing exclusion of people with impairments, for example, a growing number of special classes and a substantial increase in the number of people enrolling in special schools; in working life there are no signs that people with impairments have been more included over recent decades; the health status of people with impairments is still far worse than that of the general population; and there is a lack of coordination and cooperation between important actors that severely impedes inclusion, to mention but a few examples. People with multiple and/or complex impairments are especially vulnerable due to lack of coordination of care and services. People with psychiatric problems are among those who face the greatest difficulties. These facts indicate that there is a need for more forceful actions. Important measures focusing on individuals have been taken, but there is a striking absence of measures that have an effect on the structural conditions that produce exclusion and isolation.

Structural changes in the educational system to prevent private and public actors from excluding people with impairments are required, as are changes in the labour market to prevent employers from excluding people with impairments. Access to different realms of life for people with impairments is also required.

In order to provide policymakers and the government with adequate information about how such structural measures should be formulated and effectively implemented, more research is needed. Disability research has, to date not focused on the structural conditions that impede or increase exclusion of people with impairments.

4.2 One example of best practice (brief details)

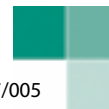
We have chosen the Act on Support and Services for People with Certain Functional Impairments (LSS) as an example of good practice, because it has played an extremely important role in including people with impairments in society. The LSS come into force on 1 January 1994 and it constitutes a substantial part of Swedish disability reform since 1993. The aim of the LSS is to facilitate daily life for people with impairments and to promote full participation in society. The people in question should themselves exert the greatest possible influence on support. The LSS describes 10 different forms of support (for the number of persons receiving support, see Tables 1 & 2): personal assistance; companion service; contact person; home respite service; short stay away from home; short period of supervision for school-children over the age of 12; children's residential homes; adults' residential homes; counselling and other personal support; and daily activities.

Data indicate that the support for people with impairments under the LSS is substantial and that it covers many aspects of daily life.

4.3 References

[Act on the prohibition of discrimination and other degrading treatment of children and pupils](#)
(2005/6:38)

Act (1993:387) concerning Support and Services for Persons with Certain Functional Impairments
(<http://www.sweden.gov.se/sb/d/108/a/1468>) (in Swedish)



Carlsson, G., Schilling, O., Fänge, A., Slaug, B., Nygren, C., Ståhl, A., & Iwarsson, S. (in press). Towards a screening tool for housing accessibility problems: a reduced version of the housing enabler. *Journal of Applied Gerontology*.

Centre for Ageing and Supportive Environment (<http://www.med.lu.se/case>)

[Equal Treatment of Students at Universities Act](#) (2001:1286)

Swedish Council for Working Life and Social Research (2001) *An Evaluation of Swedish Disability Research*. Gary L. Albrecht, Alan M. Jette, Helen Petrie, Linda Siegel with the assistance of Kerstin Carsjö (<http://www.fas.forskning.se/upload/dokument/publiktioner/pdf/handutv.pdf>)

From patient to citizen: a national action plan for disability policy (Government Bill 1999/2000:79 (<http://www.regeringen.se/sb/d/108/a/833>))

Handisam - the Swedish Agency for Disability Policy (http://www.handisam.se/upload/English/Riv%20Hindren%20English_.doc)

Jerlinder, K. Danermark, B., Gill, P. (2009) Normative Approaches to Justice in Physical Education for Pupils with Physical Disabilities – Dilemmas of Recognition and Redistribution. *Disability & Society*. 24 (3), 331-42. DOI: 10.1080/09687590902789495

Jerlinder, K. Danermark, B., Gill, P. (in press 2009) Swedish primary school teachers' attitudes to inclusion – the case of PE and pupils with physical disabilities, *European Journal of Special Needs Education*.

Lewin, B., Westin, L. & Lewin, L. (2008) Needs and visions in disability care. *Scand. J. of Disability Research*. Vol. 10, No. 4, 237-257.

Möjlighet att leva som andra. Ny lag om stöd och service till vissa personer med funktionsnedsättning (The chance to live like everyone else. New law on support and services for some people with impairments.) (<http://www.regeringen.se/sb/d/10057/a/109952>) (in Swedish)

Möller, K. (2008) *Impact on participation and service for persons with deaf-blindness*. Linköping & Örebro Universities, Swedish Institute for Disability Research.

The National Board of Health and Welfare (2007) Persons with Certain Functional Impairments – measures specified by the LSS 2007.

Möller, K. Eriksson, K., Sadeghi, A., Möller, C. & Danermark, B. (in press, 2009) Long-term ophthalmic health care in Usher Syndrome type I from an ICF perspective. *Rehabilitation & Disability*.

Rosenberg, D., Lindqvist, R. & Markström, U. (2008) The social location of need - surveying psychiatric disability in the community. *Scand J. of Disability Research*, Vol. 11, No. 1, 2009, 1-16.

Rydberg, E., Coniavitis Gellerstedt, L. & Danermark, B. (2009) Toward an Equal Level of Educational Attainment Between Deaf and Hearing People in Sweden? *Journal of Deaf Studies and Deaf Education*. doi:10.1093/deafed/enp001

Strandberg, T. (2009). Adults with acquired traumatic brain injury: experiences of a changeover process and consequences in everyday life. *Social Work in Health Care*, 48, 276-297.

Tideman, M. (2009) Samhället och disagnosen utvecklingsstörning (Society and the Diagnosis of Intellectual Disability). In Granlund, M. *Boken om utvecklingsstörning*. (The Book about Intellectual Disability)



Socialdepartementet (Ministry of Health and Social Affairs), [Welfare in Sweden: The Balance Sheet for the 1990s](http://www.regeringen.se/sb/d/108/a/885) (<http://www.regeringen.se/sb/d/108/a/885>) Departementsserien (Ds) Ds 2002:32

The National Board of Health and Welfare (2009) Persons with Certain Functional Impairments – measures specified by the LSS 2008

The Swedish Institute for Disability Research (<http://www.ihv.se>)

[The Swedish National Institute of Public Health. *Unnecessary ill health* \(in Swedish with an English summary\)](#)

[The Prohibition of Discrimination Act](#) (2003:307) (http://www.ho.se/Tpl/NormalPage____847.aspx)

[Act on the prohibition of discrimination in working life against people with disabilities](#) (1999:132)

Yilmaz, M. Josephsson, S., Danermark, B. & Ivarsson, A-B. (in press, 2009) Social processes of participation in everyday life among persons with schizophrenia. *International Journal of Qualitative Studies on Health and Well-Being*