**Equally Unique’s answers to the questionnaire for the Special Rapporteur on the rights of persons with disabilities**

**Equally Unique**
Equally Unique is a Swedish Human Rights Federation focusing on the rights of persons with disabilities according to the UN Convention on the Rights of Persons with Disabilities, and the UN Convention on the Rights of the Child and the Convention on the Elimination of All forms of Discrimination against Women. The Federation was formed in December 2009 to jointly act and advocate for the right to accessibility and participation in society for people with a disability.

We do so from a human rights perspective.

Equally Unique has 6 national member associations in Sweden:

The Association of the Swedish Deafblind

The National Association for Disabled Children and Youths,

The Swedish Association of Hard of Hearing People,

The Swedish Neuro Association,

The Swedish National Association of the Deaf

The Swedish Association of the Visually Impaired.

1. **Legislation and policies** concerning **mainstream and/or specific social protection programmes** with regard to persons with disabilities
	1. **Legislative and administrative measures** **aiming to ensure access** of persons with disabilities to mainstream social protection programmes (e.g., poverty reduction, social insurance, health care, public work, housing)

Disability policy strategy for the period 2011–2016[[1]](#footnote-1)

The UN Convention on the Rights of Persons with Disabilities (CRPD) is one of the starting points for the Government’s disability policy for the period 2011–2016. However, Sweden has not incorporated the Convention into Swedish law. Laws should be interpreted by authorities and courts so that the Convention is followed. Government agencies must work actively to ensure that the disability perspective becomes an integral part of the authority‘s overall area of activity.[[2]](#footnote-2)

The Discrimination Act[[3]](#footnote-3)

The Discrimination Act regulates protection against discrimination which applies to, inter alia, the fields of working life, the supply of goods, services and housing, as well as to health and medical care and social services.

The Social Services Act[[4]](#footnote-4)

According to the Social Services Act, society‘s social services, for which the municipalities are responsible, must promote people‘s economic and social security, equality of living conditions, as well as active participation in social life. The activities must be based on respect for people‘s right of self-determination and integrity. The Act gives the municipalities the ultimate responsibility for ensuring that those who reside in the municipality receive the support and assistance they require.[[5]](#footnote-5)

The Act concerning Support and Service for Persons with Certain Functional Impairments[[6]](#footnote-6)

This act is intended to guarantee good living conditions for persons with extensive and permanent disabilities, as well as to guarantee that they will receive the help they need and that they can influence the support and services they receive. The activities must be of good quality and conducted in co-operation with other affected social bodies and authorities.[[7]](#footnote-7) The activities must be founded on respect for the individual‘s right of self-determination and integrity. To the greatest possible extent, the individual must be granted influence and co-determination over initiatives that are provided.

The act covers ten defined initiatives[[8]](#footnote-8), such as advice and other personal support, personal assistance, a companion service, assistance from a contact person, relief service in the home, residence with special services for adults or other specially adapted housing for adults.

Health and Medical Services Act[[9]](#footnote-9)

The overall goal of the Health and Medical Services Act is to offer good health and care on equal terms for the entire population. [[10]](#footnote-10)

*Relating comments:*

As far as possible, the care must be designed and implemented in consultation with the patient, and it must be based on respect for the patient’s self-determination and integrity. There is some general advice from the National Board of Health and Welfare to make it easier for the patient to obtain information and take his or her own decisions. The recommendations include that personnel should have a good knowledge about the consequences of the disability when planning and implementing care.[[11]](#footnote-11)

There are well-documented discrepancies in health care provided to persons with disabilities.[[12]](#footnote-12)

In 2012, the National Board of Health and Welfare criticised[[13]](#footnote-13) the municipalities’ sheltered housing facilities, both housing under the Social Services Act and housing under the Act concerning Support and Service for Persons with Certain Functional Impairments. In the agency’s view, the staff needs to learn more about the health and medical care area, and sometimes need a closer link to health and medical care organisations. In some cases, the agency has directed criticism at activities on the grounds that they lack the requisite staff for the provision of quality care.[[14]](#footnote-14)

Employment Protection Act[[15]](#footnote-15)

Employees in Sweden are covered by legal protection against unjustified dismissal through the requirement for reasonable grounds.[[16]](#footnote-16) This covers everyone, including employees with disabilities.

Employees who utilise certain labour market policy support measures on the open labour market are covered by the Employment Protection Act. Disabled employees who e.g. receive wage subsidies enjoy the same employment security as other employees, for example. However, persons who have development employment, sheltered employment with public sector employers or employment with Samhall AB are not covered by this Act.[[17]](#footnote-17)

*Relating comments:*

In 2013, only 44 percent of those with reduced work capacity were employed[[18]](#footnote-18) compared to the 77 percent of non-disabled population.[[19]](#footnote-19)

Ordinance on special measures for persons with disabilities entailing a reduced capacity to work[[20]](#footnote-20)

Special support is regulated in the Ordinance respecting special contributions for persons with disabilities entailing a reduced capacity to work. The *Swedish Public Employment Service* is tasked with working to compensate for the reduced working capacity of persons with disabilities.

The initiatives primarily consist of employment with wage subsidies, sheltered employment with Samhall AB, sheltered employment with public sector employers, security employment and development employment. This Ordinance also regulates financial support for items other than wage costs. This includes support for vocational assistive devices, personal assistance, arrangement subsidies, special introduction and follow-up support (Supported employment) as well as special support when starting up business activities.[[21]](#footnote-21)

Act on housing adaptation[[22]](#footnote-22)

This act aims to provide the opportunity for persons with disabilities to live independently in their own homes through contributing to the adaptation of housing facilities.

* 1. **Institutional framework in charge of its implementation**

The municipalities and the county councils[[23]](#footnote-23)

The municipalities are responsible for issues such as physical planning, infrastructure, housing, welfare services such as, care for persons with disabilities, and health and medical service. The county councils are responsible for issues such as health care. The municipalities and the county councils are both responsible for the regional and local public transport.

The Government

The *Swedish Agency for Participation[[24]](#footnote-24)* was established in order to provide support to the Government in the implementation of disability policy.

Government agencies

Government agencies, each responsible for one sector of society, have been specially commissioned to implement the disability policy within their respective sectors. These authorities must work actively to ensure that the disability perspective becomes an integral part of the authority‘s overall area of activity.[[25]](#footnote-25)

* 1. **Creation of disability-specific programmes** (such as disability pensions, mobility grants or others)

Disability compensation

Disability compensation is a form of financial support that is intended to cover the additional costs that a disability can entail. A person can also receive disability compensation due to a need for assistance.

There are various forms of benefits available for those who have a disability, in accordance with the Social Insurance Code[[26]](#footnote-26): assistance benefit, disability allowance, work aids and special high-risk protection, car allowance, and sickness compensation.

The Regulation on rehabilitation compensation[[27]](#footnote-27) and the Regulation on grants for work aids[[28]](#footnote-28) contain provisions in accordance with the social insurance code.

1. **Information** on **how** persons with disabilities are **consulted and actively involved in the *design*, *implementation* and *monitoring* *of* social protection programmes**

There are formal consultancies government/DPOs, governmental agencies/DPOs, municipalities/DPOs. They are inclusive and taken into account to a varying degree.

1. **Information** in relation to **difficulties** and **good practices** **on the *design*, *implementation* and *monitoring* of mainstream and/or specific social protection programmes** with regard to persons with disabilities, including:
	1. **Conditions of accessibility** and the provision of **reasonable accommodation**

It was reported[[29]](#footnote-29) in 2013 that there were many remaining obstacles in Sweden. In 2003, the Swedish Parliament accepted a goal of correcting so-called "easily remedied obstacles" by 2010. At the end of 2010, the Swedish municipalities reported that only half of the identified easily remedied obstacles had been addressed. After that, the municipalities considered that these easily remedied obstacles to accessibility will not be removed until 2016. It is particularly worrying in this context that the premises that are worst affected from an accessibility perspective are schools, health centres and social services offices.[[30]](#footnote-30)

In the field of working life, there is a requirement to implement reasonable accommodations.

An amendment[[31]](#footnote-31) to the Discrimination Act introduced inadequate accessibility as a form of discrimination. The failure to take reasonable measures to increase accessibility might be deemed to constitute discrimination. However, as organizations and companies employing less than 10 employees are exempted from requirements of granting accessibility and reasonable accommodation, this lessens the practical improvements of access for persons with disabilities.

Detailed rules concerning accessibility in the built environment, both in relation to new building projects and reconstructions, are set out in the Planning and Building Act[[32]](#footnote-32). Under this law, the building must be accessible and usable for persons with limited mobility or orientation capacity. The municipalitiesare responsible for the requirements in the Planning and Building Act being satisfied on a local level. From 2011, the municipal planning and building committees are required to consider a building’s accessibility and usability for persons with limited mobility or orientation capacity when considering the planning permission application. Government adopted a new Planning and Building Ordinance[[33]](#footnote-33). Under this ordinance, county administrative boards are to monitor the extent to which the new act and its provisions are being implemented by the municipal planning and building committees.[[34]](#footnote-34)

In 2012, a new Swedish Public Transport Act (2010:1065) came into force, regulating the responsibilities of the municipalities and the county councils for regional public transport. The law includes a provision stating that regional public transport authorities are to draw up goals and measures with a specific time frame for adapting public transport to the needs of persons with disabilities. In addition, they are to specify in their transport provision programmes the lines and interchanges that are fully accessible to all travellers, including persons with disabilities.[[35]](#footnote-35)

* 1. Consideration of the specific needs of persons with disabilities within the services and/or benefits of existing programmes

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* 1. **Difficulties experienced** **by** **persons** with disabilities and their families **in** ***fulfilling requirements and/or conditions*** for **accessing social protection programmes**

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* 1. Consideration to **age, gender and race or ethnic-based differences** and possible barriers

Studies on victims of violence show that women with disabilities are particularly vulnerable.[[36]](#footnote-36)

* 1. Conflicts between the requirements and/or benefits of existing programmes, and the **exercise** by persons with disabilities **of rights such as the enjoyment of legal capacity, living independently and being included in the community, or work**

**Enjoyment of legal capacity**

According to the Swedish Parental Code, persons who are in need of support to enjoy their legal capacity are given the adequate protection and support. Under the act, stewardship is adapted to the individual needs in each case.

However, there are difficulties that need to be addressed regarding the current system of stewardship. In order to get a trustee, especially for persons with intellectual disabilities, a medical opinion is required. When such a statement has been written, it becomes difficult to cancel stewardship since intellectual disabilities do not improve medically speaking. There is a risk for persons with intellectual disabilities that they are going to have a trustee longer than necessary, because of the medical opinion. In reality it means that people cannot exercise their legal capacity in a manner prescribed in the UN Convention (CRPD).

It is also problematic that many trustees, generally speaking, do not have the sufficient knowledge regarding mental health and intellectual disabilities.

Several federations highlight cases where decision-makers, authorities and personnel of the judicial system do not apply or interpret the law in the same way when it comes to persons with disabilities as to others.[[37]](#footnote-37)

**Living independently and being included in the community**

Under the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS), activities are to promote equality of living conditions and full participation in the life of the community.

According to the Social Services Act, public social services are to promote equality of living conditions and active participation in the life of the community. Furthermore, the social welfare board shall work for ensuring that persons who, for physical, mental or other reasons, encounter difficulties in their everyday lives, are enabled to participate in the life of the community and to live as others do.

* 1. **Allocation of grants to personal budgets**

Sweden legally entitles persons with severe disabilities to a personal assistance budget (one of the ten measures of LSS for special support). A monthly sum from the National Social Insurance covers 100 percent of service costs, and enables individuals themselves to purchase self-directed personal assistance services from public and private entities. The amount of the personal assistance budget is independent of the individual’s finances. The personal assistance budget is granted in the form of assistance hours, which are based on the individual’s needs. The amount funded for 2013 was SEK275 (about €28) per hour.[[38]](#footnote-38)

*Relating comments:*

LSS can be called as one of the best laws of the world, but in practice the situation is more nuanced. Much depends on the assessments of the social insurance and how so called “basic needs” are interpreted. Growing criticisms is formulated with regard to the fact that many persons with disabilities who had been granted assistance for many years have lost it because of the changed legal practice, even though the needs have not changed.[[39]](#footnote-39)

It is also problematic that the right to the LSS measure is often decided at the court. To be able to win the case, people are in need of legal help. However, one should not need a lawyer in order to be granted the support he or she has the right to.[[40]](#footnote-40)

* 1. Disability-sensitive training and **awareness-raising for civil servants** and/or external partners

The Swedish Agency for Participation (MFD) and the Equality Ombudsman (DO) got the assignment form the Government (2015) to increase knowledge and awareness of the public, the employees in the public sector, the private sector, concerning the content of the UN Convention on the Rights of Persons with Disabilities. This initiative is scheduled to be implemented between 2015 and 2017.[[41]](#footnote-41)

* 1. **Existence of complaint or appeal mechanisms**

The Equality Ombudsman (DO)[[42]](#footnote-42) is a government agency that seeks to combat discrimination, inter alia, on grounds of disability, but only very few cases are considered. Disability is a common ground of discrimination in complaints to the Equality Ombudsman. Reports mostly concern working life and accessibility of goods and services.[[43]](#footnote-43) In practice, the long period delayed legal procedures and that DO runs a only few cases, can be considered problematic .[[44]](#footnote-44)

1. **Information** or data available in your country or context of work, disaggregated by impairment, sex, age or ethnic origin if possible, in relation to:
	1. Coverage of social protection programmes by persons with disabilities

Sweden is restrictive when it comes to registering e.g. ethnic origin, so there is little data/information disaggregated on different grounds.

* 1. Rates of **poverty** among persons with disabilities

A Governmental report[[45]](#footnote-45)shows that persons with disabilities have a much lower income than the majority of the population. The report highlights that a person with a disability may also have additional costs, for example for assistive devices, medication, adaptation, assistance with practical duties, etc.[[46]](#footnote-46)

According to a report from the National Board of Health and Welfare into living conditions for certain people with disabilities, adults with disabilities who receive support from social services live under different conditions from the rest of the population. The Board considered that there is a long way to go to achieve equal living conditions for this group. This applies particularly to people in the 20–29 years age group who are receiving initiatives in accordance with the Social Services Act.[[47]](#footnote-47)

* 1. **Additional costs or expenses related to disability**
1. **Information** in relation to the **eligibility criteria** used, in your country or context of work, for accessing mainstream and/or specific social protection programmes with regard to persons with disabilities, including:
	1. **Definition of disability and disability assessments used for eligibility determination**

The term „disability” is defined differently in different pieces of legislation.

The Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) provides persons with extensive disabilities special rights regarding social services. In order to be granted an initiative in accordance with LSS, it is necessary to belong to one of the three groups of people specified in § 1 of the Act:

1. persons with an intellectual disability, autism or an autism-like condition;

2. persons with a significant and permanent intellectual functional impairment following a brain injury in adult life caused by external violence or a physical illness; or

3. persons with other permanent physical or mental disability that are obviously not due to normal ageing, if these are major and cause significant difficulties in living day-to-day life and consequently a significant need for support or service. [[48]](#footnote-48)

* 1. Consistency of the eligibility criteria among different social protection programmes
	2. Use of income and/or poverty thresholds
	3. Consideration of disability-related extra costs in means-tested thresholds
1. En strategi för genomförande av funktionshinderspolitiken 2011– 2016. <http://www.haninge.se/upload/70713/En-strategi-for-genomforande-av-funktionshinderspolitiken.pdf> [↑](#footnote-ref-1)
2. Förordning (2001:526) om de statliga myndigheternas ansvar för genomförande av funktionshinderspolitiken [↑](#footnote-ref-2)
3. Diskrimineringslag (2008:567) [↑](#footnote-ref-3)
4. Socialtjänstlag (2001:453) [↑](#footnote-ref-4)
5. Socialtjänstlag (2001:453) 1., 2. Kap. [↑](#footnote-ref-5)
6. Lag (1993:387) om stöd och service till vissa funktionshindrade (LSS) [↑](#footnote-ref-6)
7. LSS, § 6 [↑](#footnote-ref-7)
8. LSS, § 9 [↑](#footnote-ref-8)
9. Hälso- och sjukvårdslag [↑](#footnote-ref-9)
10. SFS 1982:763, § 2. [↑](#footnote-ref-10)
11. Initial reports submitted by States parties under article 35 of the Convention on the Rights of Persons with Disabilities, Sweden, Implementation of the Convention on the Rights of Persons with Disabilities, 2011 [↑](#footnote-ref-11)
12. Handisam, 2013, p. 40-41. [↑](#footnote-ref-12)
13. National Board of Health and Welfare: Current status and trends in the health and medical care services and social services, report, 2012 [↑](#footnote-ref-13)
14. List of issues in relation to the initial report of Sweden, Replies of Sweden to the list of issues, 2014 [↑](#footnote-ref-14)
15. Lag (1982:80) om anställningsskydd [↑](#footnote-ref-15)
16. Employment Protection Act, SFS 1982:80, § 7. [↑](#footnote-ref-16)
17. Initial reports submitted by States parties under article 35 of the Convention on the Rights of Persons with Disabilities, Sweden, Implementation of the Convention on the Rights of Persons with Disabilities, 2011 [↑](#footnote-ref-17)
18. Handisam, 2013, p. 23. [↑](#footnote-ref-18)
19. Swedish Public Employment Service, January 2014 [↑](#footnote-ref-19)
20. Förordning (2000:630) om särskilda insatser för personer med funktionshinder som medför nedsatt arbetsförmåga [↑](#footnote-ref-20)
21. Initial reports submitted by States parties under article 35 of the Convention on the Rights of Persons with Disabilities, Sweden, Implementation of the Convention on the Rights of Persons with Disabilities, 2011 [↑](#footnote-ref-21)
22. Lag (1992: 1574) om bostadsanpassningsbidrag [↑](#footnote-ref-22)
23. There are currently 290 municipalities and 21 county councils in Sweden. [↑](#footnote-ref-23)
24. Myndigheten för delaktighet. Formerly called as Swedish Agency for Disability Policy Coordination (Handisam) which was established by the Government on 1 January 2006. [↑](#footnote-ref-24)
25. Förordning (2001:526) om de statliga myndigheternas ansvar för genomförande av funktionshinderspolitiken [↑](#footnote-ref-25)
26. Socialförsäkringsbalk (2010:110) [↑](#footnote-ref-26)
27. Förordning (1991:1321) om rehabiliteringsersättning [↑](#footnote-ref-27)
28. Förordning (1991:1046) om bidrag till arbetshjälpmedel [↑](#footnote-ref-28)
29. Handisam reported in its 2013 review of the Strategy of disability policy. [↑](#footnote-ref-29)
30. Equally Unique: Submission and comments on the Written replies by the government of Sweden to the list of issues CRPD/C/SWE/E/Q1, 2014 [↑](#footnote-ref-30)
31. The Swedish Parliament has adopted the amendment which came into force on 1 January 2015. [↑](#footnote-ref-31)
32. Plan- och bygglag, 2010:900 [↑](#footnote-ref-32)
33. Plan- och byggförordning (2011:338) [↑](#footnote-ref-33)
34. List of issues in relation to the initial report of Sweden, Replies of Sweden to the list of issues, 2014 [↑](#footnote-ref-34)
35. List of issues in relation to the initial report of Sweden, Replies of Sweden to the list of issues, 2014 [↑](#footnote-ref-35)
36. Initial reports submitted by States parties under article 35 of the Convention on the Rights of Persons with Disabilities, Sweden, Implementation of the Convention on the Rights of Persons with Disabilities, 2011 [↑](#footnote-ref-36)
37. Handikappförbunden: Svenska funktionshindersrörelsens alternativrapport till FN:s kommitté för rättigheter för personer med funktionsnedsättning, 2011 [↑](#footnote-ref-37)
38. <http://zeroproject.org/policy/sweden-3/> [↑](#footnote-ref-38)
39. <http://assistanskoll.se/20131104-Akademikerfrbundet-SSR-Gr-om-LSS--FN-konventionen.html> [↑](#footnote-ref-39)
40. <https://autismasperger.wordpress.com/2012/07/04/lss-lagen-som-sallan-fungerar/> [↑](#footnote-ref-40)
41. <http://beta.regeringen.se/contentassets/0635384110984d7b9385a66343ac112a/uppdrag-om-kommunikationssatsning-om-rattigheter-for-personer-med-funktionsnedsattning-s20152415fst> [↑](#footnote-ref-41)
42. Diskrimineringsombudsmannen [↑](#footnote-ref-42)
43. <http://www.do.se/Documents/rapporter/%C3%85rsredovisning2013DO.pdf> [↑](#footnote-ref-43)
44. <http://www.srf.nu/informationsmaterial/vara-tidningar/nyhetsbrev/thomssons-nyheter-2015/thomssons-nyheter-04/> [↑](#footnote-ref-44)
45. Fattigdomen i Sverige och EU [Poverty in Sweden and the EU], 2010. [↑](#footnote-ref-45)
46. Initial reports submitted by States parties under article 35 of the Convention on the Rights of Persons with Disabilities, Sweden, Implementation of the Convention on the Rights of Persons with Disabilities, 2011 [↑](#footnote-ref-46)
47. Initial reports submitted by States parties under article 35 of the Convention on the Rights of Persons with Disabilities, Sweden, Implementation of the Convention on the Rights of Persons with Disabilities, 2011 [↑](#footnote-ref-47)
48. Lag (1993:387) om stöd och service till vissa funktionshindrade, 1 §  [↑](#footnote-ref-48)