



2.15 Sweden

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2.15.1 Overview

HSO was asked if we wanted to participate as a national partner of the FORTUNE project. We accepted this invitation, and the tasks have been carried out by Ingemar Färm.

An inquiry was sent out to all disability organisations (42) entitled to Government grants and all co-operative disability organisations in the county councils (24). A similar inquiry was sent to 14 Government authorities, 4 public organs and companies, which are not authorities, all disability research institutions, all universities and all institutes of technology and 3 central organisations, with tasks within the disability field.

We have received replies from 9 disability associations, 6 co-operative disability organisations in county councils, 7 government organizations, 4 other public bodies, 5 disability research institutions and 1 central organisation. In addition to this HSO has earlier collected information about the representation of disability organizations in different government bodies. A project report that The Swedish federation of Disabled Persons, DHR, has been produced together with the Swedish Handicap institute, EFFECTIVE END-USER AND CONSUMER INFLUENCE IN STANDARDISATION.

Important authorities, which have not responded, are for instance the national labour Market Board and National board of Health and Welfare. The large public companies Swedish Telecom and Samhall have not answered and the same goes with the federation of county councils and the Swedish associations of local authorities. Some of them that have not answered the inquiry have obviously misunderstood the purpose and therefore abstained from answering or given a misleading answer.

As a conclusion we can say that the organizations of disabled people on all levels in the society (state, counties, municipalities) since long have had functioning ways of co-operation with the authorities. These are:



- give replies on reports that the authorities have sent to the organizations. HSO gets about 50 such requests each year. Besides some of the member organisations in HSO give replies within their special fields.
- participate in investigations and committees set up by the authorities. HSO participates in 8 such committees. Besides some of the member organizations in HSO sometimes has been given seats in committees in their special fields
- participate in co-operating bodies with the authorities. There is no overarching co-operating body at the national level but in 12 central authorities there are such bodies, while they are missing in about half a dozen others.
- participate in reference-, working- and assortmentgroups about technical aids, standardisation and R&D.

The tendency is that the organizations are offered to participate in working- and referencegroups with clearly defined tasks instead of overarching co-operating bodies between the organizations and the authorities. These bodies have had hard to find tasks as well as ways of working. In the county councils and municipalities there is a clear tendency to tie the interests of the end-users to separate activities as clinics, centrals for technical aids, separate local administrations at the expense of the overarching advisory bodies on disability questions.

There is still a long way to go before the authorities, even those who have their main interests in the disability-field, regard it as natural to ask for the end-users competence and experiences. Neither the researching institutions regard it as natural even if it today is a clear tendency to approach the disability organizations. The representatives of the organizations of end-users are hardly never been given training in order to be able to participate in the best way in the co-operation.



2.15.2 *Report*

2.15.2.1 **National level**

Since a long time ago, in Sweden, there has been a system, where the authorities are in different ways co-operating with representatives of groups, which are affected by the authorities' activities. Examples of such forms of co-operation are:

* **Official proposals referred for consideration.** The government refers their inquiries to among others organisations which are affected by the inquiries' proposals. HSO is such a body and replies to about 50 proposals per year. Experts at the HSO office elaborate the answers after contacts with representatives of the concerned disability associations. Finally the HSO's board decides on the contents. Separate member organizations sometimes are being asked for their opinions in matters which are of special interests for their membergroups.

There is a tendency that the authorities demand for shorter time to reply, which makes the democratic process more difficult. Another tendency is to replace comments to these proposals with hearings, which also makes it more difficult to anchor the work.

***Participation in Governmental committees:** Groups concerned are often offered but not always participation as a member or an expert in governmental committees. For the time being HSO is represented in 8 of these committees. There is a tendency that the organisations are more seldom offered a seat in the inquiry itself but instead the government is setting up reference groups, which are consulted, in specific issues.

***Membership in boards of government bodies:** As far as to the end of 1980s it was usual that organisations could appoint members in the boards of government bodies. Since then there has been a development towards boards with either MP's or independent "experts". The disability organisations are participating in a government agency board, the national Board for Consumer policies, in 2 research councils, in



the government Telematics Company Handitek's board and in the Swedish Handicap Institute's board. In the latter case there are proposals to remove the disability organisation's representatives from the board. In Samhall, a government company group which provides work for persons with disabilities, there are individuals with disabilities taking part in their central and some regional boards. In principle they participate only as private persons.

***Co-operative committees with authorities/public bodies:**

Earlier there was a central consulting body in disability-questions between the state and the organizations of people with disabilities, "Statens handikappråd". It was abolished in 1995 and has not yet been replaced by another body.

Tens of authorities/public bodies with tasks within the disability field have set up some form of co-operative committee. These consist of representatives of authorities and one or more representatives of the disability organisations. The co-operative committees are as follows:

- the disability committee of the National Board of Health and Welfare
- the disability delegation of the National Social Insurance Board
- the delegation of vocational rehabilitation within the National Labour Market Board
- the reference group within the Samhall group
- the Swedish Handicap Institute's co-operative committee
- the Swedish State Railways' consulting group
- the consulting group in the Scandinavian Airlines System, SAS
- the National Road Administration's consulting delegation in disability issues
- the consulting body of the National Swedish Agency for Special Education



- the consumers consulting body in the Swedish Standards Institution



- the consulting group in the Swedish board for Post and Telephone
- the council of Working live Research reference group

A half a dozen authorities with activities within the disability field have not that kind of co-operative body. The co-operative committees have been criticised for not being provided sufficient concrete assignments. They have usually only been a body of mutual information.

***Working groups.** The most concrete co-operation between authorities and disability organisations is taking place in some authorities' and other public bodies' special working groups. Such working groups are especially common within technical aids and standardisation activities. We have located the following groups:

The Swedish Handicap Institute (HI)

HI's user forum for speech-, visually-, hearing-, or cognitive disabilities. 23 individual disability organisations are members of this user forum, which meet once a month.

HI's R&D-council has 4 representatives for the disability organisations.

HI's reference group on IT-issues has 9 representatives for the disability organisations.

HI's consulting group on telecommunications has 7 representatives for the disability organisations. The group replaces the co-operative group that the Swedish Telecom had together with the disability organisations before they were restructured on a commercial basis.

HI's assortment groups HI has in a range of areas set up assortments or reference groups for individual groups of products or working areas. Those disability groups concerned are always represented in these groups. Now there are the following groups:

- The Swedish National Society for persons with Mental Handicap,
FUB's technical aid committee of persons with mental disabilities
- Reference group hearing



- Reference group building- and society planning
- Assortment group electric wheel chair
- Assortment group epilepsy
- Assortment group hearing aids
- Assortment group hearing technical aids
- Assortment group insulin pump
- Assortment group communication aids for people with physical, speech and mental disabilities
- Assortment group manual wheel chair
- Assortment group vision
- HI's standardisation work: During the years HI has had a number of working groups within the standardisation area. Co-operation with the disability organisations has taking place in different forms.

2.15.2.2 Organizations for standardisation

- Information technology standardisation has by commission of the board for Post and Telephone set up a working group on standardisation in the area of telecommunication and disability. The group includes 7 disability organisations.
- The Swedish Crane and Lift Standardisation has a national workinggroup, where among others organizations for person with disabilities are participating.

Other bodies

- The Disability Ombudsman's (HO) working group on elaborating a manual for local authorities and county councils.



- The National Board of Housing, Building and Planning's building council that are a consulting body but with concrete tasks to take a stand to proposals of rules for building activities. In addition to other interest groups disability organizations are also taking part in the building council.

* **Co-operation with other organisations:** The disability organizations are looking after their interests in different matters by co-operation with other organisations. HSO is e.g. a member of the Swedish Consumer Association, which is an umbrella organisation of Swedish popular movements on consumer issues. Swedish Consumer Association has e.g. working groups on food issues, general services and standardisation issues. These working groups are promoting the interests of the users within their fields. HSO is taking part in these mentioned groups.

* **Project activities:** Several authorities and public bodies have reported that they have co-operated with disability organisations in different projects. Projects have often been established on the initiative of the organisation while the authority is a financier or a partner.

2.15.2.3 Regional level

* **County councils:** The county councils are responsible authorities of first of all the health and medical care and the public transport in the counties. The Health and Medical Services Act provides that the counties shall co-operate with among other the disability organisations in health and medical care issues. On the other hand, it is not regulated how this co-operation shall look like. We know that the co-operation is functioning badly in many areas but others works rather well.

In Uppsala county council the county council and the disability organizations have signed an agreement on influence. The main principle in the agreement is that the county council, its administration and clinics have an obligation to inform the disability organisations about changes, which takes place in their respective interest areas.



The disability organisations has in their turn a possibility within certain timelimits to ask for a discussion with the county council to give their points of views on the proposals.

In Örebro county's county council there are user councils within the following areas, where disability organisations are represented:

- Interpreter services
- Centrals for persons with defected sights
- Child and youth habilitation
- Adult habilitation
- Rehabilitation and Medical department
- 3 psychiatric clinics
- Administration of habilitation

In all counties there are special councils for disabled people, LHR, with representation from the county council, local insurance office, county labour board and the disability organisations. The county councils has usually an employed disability adviser as a secretary and a rapporteur in LHR.

In conjunction with the establishment of the new large county councils Skåne and Västra Götaland the forms of co-operation are examined.

* **Disability research:** There are tens of disability research institutions connected to Universities and Technical Institutes all around the country. Co-operation with disability organisations is unequal but a discussion within the institutions and their common association will lead to an increase of users influence. In Harec at the University of Lund they have a panel of users with 9 representatives of disability organisations. Besides the most common form of co-operation is to tie a one or more users to an on-going research project, as reference persons or the like.

2.15.2.4 Local level



In the Social Services Act (SoL), Act concerning Support and Service for persons with Certain Functional Impairments (LSS) and Planning and Building Act (PBL) there are directives which says that the municipalities must co-operate with the user organisations. The forms of how this will be done are not regulated.

Both the disability organisations and the Handicap Ombudsman are working very actively to make the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities to leave marks in forms of tangible results in the local authorities. One way of doing this is to elaborate municipal action programs. It must emerge from these programs how the user influence will be functioning.

In most local authorities in the country there are community councils for disabled people (KHR) with representation from both the municipality and the disability organisations. KHR is only a consulting body and has been a target for a lot of criticism for only being occupied with information about such things that already are decided.

2.15.3 *Comments*

a) How are the user representative appointed? Usually an authority offers an disability organisation to appoint a representative in e.g. a working or reference group. The organisation concerned then appoint, sometimes after a nomination from the members, the person they consider the most appropriate for the mission. The offer of a seat in the working group has often been preceded by a request from the organisation of such a representation.

In some cases the authority has appointed user representatives without first having asked the organisations, at least not officially. These missions are personal in contrary to the others which are organisation's representation.

b) Have the user representatives had any training for their mission? What we have seen it has never occurred that neither the organisation that appoints the representative or the authority concerned give the representative any special training for the mission. They take for granted that those persons who are appointed have the



required knowledge. In reality, the training need is in many cases very large not at least in standardisation and technical issues, which is made clear in the DHR project report and the HSO publications about standardisation. Some sort of introduction is given in some cases. But after that it is up to the individual to get more knowledge.

c) **How is the user representation organised?** As we have shown above there are user representation in many different ways. The most common is some form of reference group or council. It becomes more common with participation in working and project groups with concrete tasks. It is regarded as more efficient and is more appreciated.

d) **Where in the project process occurs the user participation?** Most usual is participation in conjunction with policy discussions, planning, information and evaluation. The groups will often function as a sounding board or a forum of discussions and follow in many cases the actual questions from the beginning to the end.

In technical aids activities user participation is often very concrete e.g. need evaluation, participation in elaboration of specifications of requirements, product analysis and product selection, functional judgement, trial and testing, evaluation, product information and standardisation.

Some examples:

In HI's R&D-council for technical aids they make once a year an inventory of important needs for research. After that they work out proposals for HI's R&D-policy.

In HI's referencegroup for hearing-aids the group gives their opinions and proposals before HI starts the work with their plan of action

The aim for HI's consulting group on telecommunications for people with disabilities is to give consultations to HI in current matters, discuss important documents, directives and political matters within this field.



HI's assortment groups have the duties to support HI in their interpretation of technical specifications and judgements of which products that will be put up on HI's list over "Good technical aids".

The hard of hearing association writes that for the groups on hearing aids and hearing technical aids the tasks are needs and functional judgements, participation in working out functional specifications and evaluation of technical and functional testings.

The board for Post and Telephone standardisationgroup together with the Information Technology Standardisation have the duty to inform about existing standards, work out new standards, participate in standardisation and identify needs of standardisation.

The Crane and Lift Standardisation national workinggroup is an expertgroup with the task to work for a good European standard. The end-user representatives participate in judgement on needs, functional judgements, opinions on developement, design and production and make risk analysis.

The duty for the HO workinggroup on writing a manual for the municipals is to use the different knowledge's and experiences to assist in producing good basis for the planning in the county councils and the municipals.

The Council of Working live Research reference group has to put forward proposals on important areas within which the Council ought to take initiatives for R&D-activities and assist with ideas on information and dissemination of knowledge.

In the county council of Gävleborg there are three user councils, where the organisations for people with disabilities can put forward user opinions on current matters.

In the assortment groups in the county council of Västmanland the end-users participate in judgement of needs, product analysis and functional judgements.

e) **Working methods** What we have seen from the answers the work are taking place mainly in forms of discussions in the working groups. Here the products are presented or demonstrated and the results from e.g. the R&D work are reported.



The user representatives' task is then to critically examine these reports in the lights of own experience or do easier inquiries among their own organisations' members. In the assortment groups it is common with direct participation in user testing. In some cases it is the user himself who carry the testing through by using the product in his own daily life.

Many disability organisations have carried out comprehensive own projects, were they have studied the usability of new products or methods. The experience from these projects is then used in contacts with the authorities. Some projects are carried out together with the authorities.

User oriented research has been tested in many places in the country first of all in forms of research circles, a pamphlet is attached to the report.

The last comments

In most situations where disability issues are under discussion today is user participation mentioned but there are few concrete proposals. The big governmental committee on Health and medical care year 2000, HSU 2000, has recently presented a report on the influence for the patient. As a conclusion we can say that both in this and other reports they are more eager to widen the individuals influence than to give his organisation the possibility to influence in a larger and more principal perspective.

From the point of view of the organizations it is of course a good thing that influence from the patient increases over such matters that are of importance in the daily life. But we can also see that the individual has a weak position in relation to scientists and doctors, authorities and companies. It is therefore important that the greater influence for the individual is completed with a greater influence for the users organizations. This influence has to come in so early as possible in the planning process and then follow the development up to the finished product or service.

From the answers on the enquiry we can see that several public authorities outside the disability-sector turn on to other public authorities within the disability-sector in order to get a user perspective. Both HI and HO sometimes have to take this roll. It is



important that the public authorities get the information that it is only the organizations of persons with disabilities, that can function as a representative for the users and their experiences. This interpretation has a strong support in the UN Standard rules. Above all the Standard rules ought to function as norm, when we talk about the influence for the user over such matters that influences his own situation.

Those working most with user participation are the disability organisations themselves. HSO has e.g. carried out a big “influence project“ and projects about standardisation and consumerpolicy. Just now we have a discussion about starting a new big project on the influence for the patients and the users. But the demands of more real influence and a more substantial co-operation is growing stronger within the disability organisations.

A question in some of the answers on the inquiry is the financing of the participation for the user. At least in the standardisation institutions it has been common that the participating companies, authorities and organizations has to pay for their participation. From the disability movement we regard it in the totally opposite way. We regard that the authorities and standardisation institutions ought to view the participation from the user organisations as a unic expertknowledge, which they must present resources to in order to gain form the best of their competence. The disability organisations are not partners, who can make money from products or services being accessible for persons with disabilities. But we can help authorities and companies so that their products and services function better for them who has the need of them.

At last I will refer to the project report from DHR. It has not been discussed in HSO but the proposals in the report are just alike those that has been discussed in HSO.

2.15.4 *Enclosures*

Reply from the Swedish Handicap Institute, Information technical standardisation, the Swedish Consumer Association and The Swedish National Society for Persons with Mental Handicap

Reports from HSO’s influence project among others and



The DHR report

The above enclosures are provided in separate paper publications.