

# **PEOPLE WITH DISABILITIES**

## **AS DEPICTED BY THE MEDIA**



The aim of this handbook is to show what can be done to initiate a discussion about the way in which so-called marginalised groups are represented in the media.

The manual is the result of a dedicated collaborative effort between the Swedish Disability Movement, The Swedish Radio Corporation, and Dagens Nyheter, the leading daily newspaper in Scandinavia.

The idea is not to present an absolute truth, but rather to stimulate a debate in which all parties concerned may feel that they have something to learn.

Per Frykman, Project Manager  
The Swedish Disability Federation

## The image of the disabled as conveyed by the media

What significance does the image of people with disabilities have? Are journalists responsible for the image that is conveyed? These are two of the central issues in this manual. Research shows that the image of disabled people is fairly consistently one-sided.

Our wish is to encourage journalists and photographers to portray disabled people not solely on the basis of their physical, mental, social or medical condition.

Our aim is to do this without complaint or any semblance of superiority. We wish to focus on the individual, the human being – not the disability itself. We have, by means of a random sampling, examined the way in which two important media companies, the Swedish Broadcasting Corporation (SR) and Dagens Nyheter (Dagens Nyheter) describe people with disabilities and handle related issues.



As an illustration of the project, we have taken a couple of well-known examples from literature and film.

Most people are familiar with "Hunchback of Notre Dame". But apart from his hunchback, what else do we know about him? Another example is the film "Rainman" with Dustin Hoffman and Tom Cruise, where Dustin Hoffman plays an autistic man with hidden talents, e.g. adding up the numbers on the cards in a game of blackjack. But though the film gives us a deeper insight into autism, again it is the disability that is highlighted.

But there are some positive examples too; for instance, the TV series "The West Wing" in which Martin Sheen plays the part of President Bartlet, who turns out to have MS. This raises a string of interlocking questions. Why is it so shameful to hide his illness the way he does? On the other hand, it is interesting that the

President and his illness is taken up in a popular, award-winning TV series such as this. The President is first and foremost The President, not disabled, who in spite of everything, has fought his way to the position of the most powerful man in the world.

*Whose perspective?*

The media's daily news reporting features persons with varying disabilities. In most cases the impairment is seen from the viewpoint of non-disabled persons (i.e. the reporters and producers). Disabled persons, or their organisations, are seldom, if ever, consulted or invited to participate in conjunction with a TV reportage. Documentaries and news items are mostly presented from a "despite it all" perspective.

A recently published doctoral thesis examines programmes and features produced by Swedish Public Service Television, from its start, in 1956, to the year 2000. Of the total amount of transmitted material, less than half a percent was devoted to persons with disabilities. The way in which they are described is also extremely debatable. The fact that they do not have a common lifestyle is nearly always pushed into the background. What can they themselves and their organisations do? In all honesty, they should reflect on their own attitude to the media. For unless they cease to represent themselves as victims or cripples, they cannot expect others to see them differently.

*By Per Frykman*

# People with disabilities in the Swedish media

*A study of Sveriges Radio and Dagens Nyheter*

*By Elin Gardeström*

Since the media are an essential normative factor, how do they represent people with disabilities? I have tried to answer that question by examining the Swedish public service radio (Sveriges Radio) as well as the newspaper Dagens Nyheter.

In my study, I have perused articles and broadcast scripts, and among other things noted the frequency with which disabled people themselves participate and the reasons for drawing attention to them.

I have examined their roles with guidance from a Swedish doctoral thesis entitled "From close up nobody is normal" by media researcher Karin Ljuslinder. It describes how Sveriges Television depicts people with disabilities on the basis of four archetypes from folktale: the hero, the victim, the eternal child and the villain. Having read only a few of the texts, my representation can hardly be called scientific, and should rather be seen as a spot check.

## *Representation in Dagens Nyheter*

Dagens Nyheter is Sweden's largest morning paper. A search in Presstext, February 2002-February 2003, for the word "disablement" and "handicap" resulted in 757 matches, the majority of which gave the word "handicap". A review of 86 selected articles shows that journalists write very well, sensitively and ambitiously. There is, however, widespread confusion where conceptual terminology is concerned. Furthermore, critical questions are never addressed to disabled people or their organisations.

## *Some facts*

Disabled people appear in 35 (of the 86) articles. There is an equal gender distribution: approximately as many men as women are interviewed. 34 articles reflect the opinion of an expert regarding the situation of disabled persons. The expert is either a civil servant, a researcher, a doctor or a politician. 23 articles refer to people with a mental impairment. Dagens Nyheter appears to take particular interest in this category of disability, which includes some 37,000 people in Sweden. An explanation for this can be sought in a much debated television reportage at the time about a mentally impaired couple whose child has been taken into care by the social authorities.

The most common motive for writing about someone with a disability is in their capacity of economic object (15 articles). Which is to say that the interest in them is bound up with a lack of resources at national, regional or municipal level. The housing issue allied with contempt of court belongs in this domain. Other relatively common reasons for the interest are accessibility (9 articles),

and assistive technology (9 articles). There are also didactic articles on various diagnoses (7 articles).

### *Conceptual confusion*

It is not easy to work as a journalist in a world where Swedish disability associations who themselves have the word "handicap" in their organisation name insist on a common usage of the term "disabled" rather than "handicapped". Some persons also prefer to call themselves handicapped.

In an effort to dispense with stigmatising descriptions words have been altered through the ages; e.g. from cripple and idiot to wheelchair-borne and mentally disabled. But it can be problematic for the journalist – to use words that are not insulting but which can be readily understood by the readers. Who understands what, for instance, a neuropsychiatric diagnosis is? Dagens Nyheter journalists have a variety of solutions when it comes to the concepts they use, and therein lies the confusion.

In the 86 articles I have read it is clear that "disability" and "handicap" are often used synonymously. Within the Swedish disability movement, much of the political dimension lies in the difference between these concepts; a person is said to be disabled, but is handicapped in an environment where the disability is an impediment. There is nothing categorical about this, it is merely a statement of the fact that the terms are used in different manners.

People with a mental impairment are referred to in a variety of ways: mentally handicapped, retarded, intellectually disabled, or people who cannot manage entirely on their own. None of these concepts are considered offensive, even though the respective organisations prefer a strict observance of the expression "persons with mental disabilities".

In one instance, Asperger's syndrome is described as a mental illness, which is inaccurate. In another article, Asperger's and ADHD are characterised as mental handicaps, which is inappropriate. Sometimes, the solution is to explain the diagnosis or to describe the injury.

One brief news item says "woman in wheelchair". Another problem resides in the fact that authorities have introduced their own concepts, such as "work handicap", which further complicates the issue. An example is: "*Eagerness to Economize Hits the Handicapped.*" The National Board of Health and Welfare in Lycksele to save 22 million.

The demand for cut-backs in expenditure affects the 67 mentally handicapped people whose daily wage of 15 kroner has been stopped. At the same time as the politicians are raising their own salaries.

-They ought to be ashamed of themselves, says Kjell Lundgren", work-disabled mechanic".

In five lines, three different terms are used to describe the same person. Does

it further our understanding of who these people are? In conclusion, it can be said that the terminology used is a universal problem, and that the risk of conceptual confusion in newspapers could have the effect of making people appear stranger than they are.

### *How are people with a disability referred to?*

12 of the Dagens Nyheter articles present the persons interviewed as victims of policy-making. They are about mentally impaired people losing their bonus money when local authorities need to save. Authorities taking the children of retarded parents into care. The failure of local authorities to build accommodation for the disabled. In one case, it is a deaf electrician at the mercy of an unsympathetic private employer. In another, the villain is the media, who portray the disabled in a disadvantageous light.

Two of the archetypes described in the introduction are easily identified, as the disabled person is often at the mercy of an evil society. Sometimes, those archetypes are used automatically, without prior thought.

In one of the articles, about the stopping of extra bonuses, the interviewee is a businessman who employs intellectually impaired workers. The fact that he may have a responsibility for paying them is not brought up, rather all the criticism is levelled at the local authorities which withdrew the salary subsidy.

Dagens Nyheter interviews several vociferous and influential individuals from the disability movement, who speak, in their primary role as representatives for their organisations. A wheelchair-borne county council politician is interviewed about the Disability Year and a deaf actress tells about her work in a theatre ensemble of deaf actors. One man has been singled out on account of being a consumer. He is blind, and therefore unable to take the rubbish to the recycling station himself. Since he wants to be fully acknowledged as an environmentally-minded consumer, he insists on his rubbish being collected from his home and transported to the recycling station.

## **Representation in Sveriges Radio**

The Swedish Broadcast Company (Swedish Radio) is a public service company with 4 national and 26 local channels. A search for "disablement" undertaken in February and March 2003 in the Radio archives (ENPS), resulted in 535 matches. Of these, I have examined 89 randomly chosen manuscripts, including telegrams, announcements and reporters' commentaries.

### *Some facts*

An overwhelming portion of the scripts (73 of 89) were produced by local radio stations. Many issues relating to disabled persons are dealt with at a municipal and regional level, which explains the activity of local radio.

The majority of the scripts (53) refer to the disabled as a group despite the fact that no one from this group participates. This is apparent from the large number of telegrams. Disabled people have taken part in 25 programmes.

There is an equal gender distribution. Both representatives from the Disability Movement and private persons with disabilities have been interviewed. In 30 Features, interviews were held with an expert or a relative, who give their views on the disabled person in question, but not with the disabled persons themselves.

Though not particularly pronounced, the focus is mostly (13 scripts) on persons who have had psychiatric care – the mentally impaired and persons with an intellectual disability.

### *Profusion*

Why does the Radio draw attention to disabled people? A considerable variety of subjects are involved here: care, assistive technology, discrimination, accessibility, work and sport. The commonest interest is in the disabled as economic objects (23 scripts). By this I mean that the cost for the care and support of disabled persons is the principal focus. Often, it is about the lack of funds in state, municipality and county council; cutbacks are necessary within the area of the school for intellectually disabled; a meeting-place for the mentally impaired in Västerås must close, Vännäs municipality demands more money from the State in order to meet expenses for the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS).

Several ambitious features attempt to explain a special group's situation or why some people have special needs. Radio Jämtland introduces a programme with the words: "Have you ever thought about being a contact person for someone who is disabled?" Thereafter the listeners are introduced to Johan, the contact person and Krister who is disabled, going for a swim. After the documentary, an appeal is made for more contact persons in Östersund. A reportage by Radio 1 (P1) in Gothenburg describes the sexuality of the disabled. Other people's attitudes to this are skilfully summarised thus: "For someone who regards mentally disabled persons as small children in adult bodies, sex will naturally be a sensitive issue".

### *Names and concepts*

Just like Dagens Nyheter, Sveriges Radio is faced with the dilemma of using words that will not give offence but which will be readily understood by the listeners.

The journalists at the SR manage this very well. For the most part they use the one term "disabled" (45 scripts). Sometimes, the term is augmented by a specific diagnosis (16), and occasionally the words disability and handicap are used synonymously (11). Within the Swedish disability movement, much of the poli-

tical dimension lies in the difference between these concepts: A person has a functional disability, but is handicapped in an environment in which the disability becomes an impediment. It is this situation that has engendered the demand for a society adapted to the needs of all citizens.

Just like their colleagues at Dagens Nyheter, journalists at Sveriges Radio use numerous terms for people with a mental disability. Although none of these are wrong or offensive, they can confuse the listeners as to whom the reporters are referring to.

There are several good examples of journalists making an effort to explain various disabilities. Radio Sjuhärad, for instance, gives an excellent description of Down's Syndrome. In a news feature they manage in the time allotted to give an exact description of the diagnosis and to explain what it means in practical terms for the person in question; they also explain why the term "mongoloid" is not a happy one, and interview children and parents.

Aspberger's Syndrome, ADHD, and other diagnoses are tricky to describe. Radio Västernorrland gives a medically exact diagnosis and talks about neuropsychiatric disabilities, such as ADHD. Another local channel talks of mental diagnoses, which is less appropriate as one is apt to associate it with psychiatry. Although there is no consensus among researchers, the feeling is that it has a biological and hereditary cause.

### *How are people with a disability referred to?*

Media researcher Karin Ljuslinder maintains in her paper "From close up nobody is normal" that the journalistic method of portraying the different and the abnormal has a negative impact on disabled people. In the media they are identified with their impairment; they are their disability, their divergent body and incapacity, rather than mothers of small children, passengers, taxpayers or consumers.

Just like in Dagens Nyheter, people with disabilities are often cast in the role of victims. Common types of sequences or telegrams are about disabled persons being subjected to political cutbacks.

In most cases, disabled people draw attention because of their disability. Unless they work within the disability movement or at Samhall (sheltered workshops) they are not referred to by a title. In the following concluding announcement, "disabled" is equivalent to a title: "...said Per Olof Hedvall, project leader for Interagera at Furuboda outside Åhus. You also heard Gada Methou, disabled, and speech therapist Håkan Larsson".

There are instances of people being of interest for other reasons. One telegram is about a murder. Here the primary interest is in the person in his capacity as a murderer and not on account of his disability. A woman who miraculously survived an accident when she and her wheelchair ended up beneath an

underground train, is referred to in another telegram as "the victim of a traffic accident".

Radio Stockholm talks of customers with a disability who cannot use the post office's new service centres, thereby emphasising the customer role. It might be interesting to reflect whether such a pointed word as "customer" makes a difference when comparing the sentences "the disabled cannot use the service centres" and "customers with a disability cannot use the service centres".

### *Final comments*

I have also looked into another important aspect, namely how journalists fulfilled their investigative task with respect to people with disabilities and their organisations. Do these ever receive critical questions by Dagens Nyheter and Sveriges Radio? Judging by the newspaper articles, it is never the case - the disabled seem to always be in the right, and the same tendency can be observed in Sveriges Radio.

Journalists have placed the disabled and their organisations in a free zone, which raises a number of questions, such as why? And what does the absence of critical questioning say about the attitude to disabled people? Are they seen as equal citizens? Or is it about the news concept needing someone who is vulnerable?

It has been difficult to find any stereotyped descriptions of heroes in Sveriges Radio, since I have not been able to listen to the recorded interviews. In Dagens Nyheter there are, by analogy, several heroic descriptions of assistive technology and its ability to compensate disabilities. The success of the digital camera in the school for students with an intellectual disability. Emma, who is completely paralysed, is able to communicate with the aid of a minimeter.

Josephine controls her life with the help of her tongue; the 3G mobile phone is a hopeful sign for the deaf; Rehab dog Alba is both an aid and a friend, and so on. This special little genre on assistive technology is exuberantly positive.

Dagens Nyheter features one example of an interesting hero: a man who broke his back while bathing in a rough sea in Hawaii. The article describes his struggle with unsympathetic authorities to make a return to life and to work. It is powerful, eloquent writing and functions as the story of someone who makes it back (almost) to normality.

In her thesis, Karin Ljuslinder talks about the fact that journalists sometimes represent the disabled as being as normal as anyone else, in what she calls "normality presentations". But these presentations collide with the journalistic method of focusing on the divergent and different. Consequently, the disabled will indeed appear abnormal.

Jesper Odelberg, a famous Swedish stand-up comedian who himself has cerebral palsy, once expressed the following thought: 'Tell a person often enough that they are just like everyone else, and they will begin to realise that they aren't like everyone else.'

*Elin Gardeström is a journalist. She has worked, among other things, at Sveriges Radio and was the project leader during the setting up of the News Agency Ikapp which covers news concerning disabled people. At present, Elin is writing a Masters in History of Press ideologies.*

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## Glossary

### *Accessibility*

Accessibility is about making it possible for everyone to take part in society, notwithstanding a disability. The idea is often linked with that of removing physical obstacles. Equally important is that information be made available for all, and that everyone has the chance to communicate. For instance creating home pages on the Internet, of which everybody can partake.

### *Activity compensation*

Since January 2003, activity compensation has been paid out to 19 to 29 year-olds. The compensation is paid out during a three-month period, after which it is reviewed. The object of the new system is to counteract the passivity of young people. Those who are 30 and over now receive sickness benefit instead of an invalidity pension. The sickness benefit has no time-limit.

### *Agenda 22*

Is a method whereby local and regional government can plan a good disability policy based on the UN Standard Rules. This means that the Standard Rules in a more long-term perspective will be used to realise human rights for disabled persons.

### *Braille and other media for people with impaired vision*

Braille is used in the first place by those who have been blind since childhood. Some 100 persons in Sweden have Braille as their first written language, but the group is diminishing. Several thousand, however, use Braille as a complementary aid. Many blind people take in the written word in other ways, for example in the form of talking books or automatic speech recognition. There is a large

selection of fiction for the people with visual disability. The Swedish Association of the Visually Impaired considers that there is a great lack of other kind of information, despite the State's ambition that the blind should be able to take an active part in the society, like anyone else.

#### *Childcare allowance*

A monetary allowance to parents with disabled children. The money may be compensation for the parents having to reduce their working hours. The allowance can also be used to cover the added costs incurred for the child.

#### *Cognitive disability*

Cognition means the processes in the brain whereby we receive, process and convey information. It is about memory, orientation, problem solving, numerical ability, lingual ability and so on. Disabilities that affect the cognitive ability are, i.a., intellectual disability, brain damage, aphasia, autism, dementia, mental impairment, and whiplash injuries.

#### *Deafness*

Refers to persons who have been deaf since childhood. They often have sign-language as their first language. According to the National Swedish Federation of the Blind (SDR), about 70 deaf children are born each year in Sweden.

Deaf adults are those who have become deaf in adulthood. They do not have sign language as a first language. They may use signs as a support but are mostly dependent on written interpretation.

#### *Design for all*

Goods and services should as far as possible be available to and usable for everyone. An important starting point is that the design of products is suited to as many as possible from the beginning, instead of adjustments having to be made later on. The concept has, during recent years, been taken up in the field of Architecture and Design.

#### *Disability Allowance*

Is paid out to disabled adults below the age of 65. The benefit is meant to compensate for the extra costs that the disability entails. For instance to pay for help in the home or for purchasing assistive technology.

### *Disability Ombudsman*

The Office of the Disability Ombudsman (HO), is a national authority whose task is to guard the rights and interests of the disabled. The objective is full integration and participation in the social life and equal living conditions for persons with disabilities.

### *Discrimination*

There is no generalised law against discrimination. However, there are two particular areas in which laws apply: that of working life and higher education. The laws prohibit direct and indirect discrimination. That is to say the former applies in the case of persons receiving inferior treatment because of their disablement, the latter pertains to disadvantages owing to exterior conditions. In the area of working life it may be about making demands on applicants that are not necessary for the job, but which on the other hand exclude the disabled. Within higher education demands that appear neutral may be considered discriminatory if they make things more difficult for the disabled, as, for example those with impaired reading and writing skills who are not given enough time when taking an exam.

### *Handicap*

Earlier, a person's handicap was considered to be a characteristic. Nowadays, it is linked to the environment – the relative handicap concept. A person with impaired sight who has access to books recorded on tape is less handicapped than someone who does not have this possibility. To assess the number of handicapped persons can thus be problematic. Impaired sight, for example, is always seen as a disability, but not necessarily a handicap.

### *Functional impairment*

Permanent limitations of a person's physical, mental or intellectual capacity. This may depend on illness or injury that is either congenital or has arisen later in life. The disability is permanent whereas the handicap is variable.

### *Intellectual disability*

May depend on chromosomal change, foetal injury or other birth injury. Injuries sustained during childhood/adolescence may also lead to intellectual disability. A common factor where these people are concerned is that they require longer time than others to comprehend, to learn new things and to express their thoughts and feelings.

### *Invalidity pension*

An invalidity pension is no longer granted. See "Activity compensation".

### *LSS*

People with severe disabilities who find it difficult to manage in everyday life, may be entitled to help according to the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). Ten measures can be taken, i.a. providing a personal assistant. A big problem is that a lot of people who are entitled to help according to LSS are not accorded their rights.

### *Medical Disability*

An overall term for disability caused by chronic or lengthy illness. To this group belongs also impairment due to surgical treatment, e.g. stomy surgery. A lot of the illnesses require regular, time-consuming and tiring treatment. The disability is not noticeable on the outside. Asthma/allergies, haemophilia, epilepsy, etc, are the cause of medical disablement.

### *Mental Disability*

Lengthy impairment of social skills is a common definition of the concept. A broader explication is that mental disability applies to all those whose social circumstances are affected by their mental health. The problem can take the form of apathy, social isolation, oversensitivity to external impressions and lack of trust of other people.

### *Neurological Disability*

Impairment of the central nervous system that may lead to mobility impairment and/or cognitive problems. Diseases/injuries which cause neurological disability are, i.a. Parkinson's disease, Stroke, ALS (Amyotrophic Lateral Sclerosis) and CP (Cerebral Palsy).

### *Rehabilitation*

Exercising to ensure enhancement of the functional ability of disabled persons.

### *Rheumatism*

Although rheumatic diseases affect mainly the mobility apparatus, i.e. joints, muscles and the skeleton, they can also attack everything from the smallest eye capillary to the largest joints and vital organs. The cause is mainly inflammatory, though some rheumatic conditions can be of different origin.

### *School for students with an intellectual disability*

The school for students with an intellectual disability is for pupils who are intellectually disabled, autistic or the like and who are not expected to achieve the goals required within the ordinary compulsory-school education. It is part of compulsory education, and is divided into comprehensive school and a training school.

The comprehensive school shall as far as possible be the equivalent of normal school. The training school is for those who do not succeed in the compulsory school for students with an intellectual disability.

### *Small and lesser known disability groups*

Unusual diseases and injuries which lead to extensive disablement. Applies to 100 out of a million people at the most.

### *Swedish national action plan on disability policy*

In the year 2000, Parliament approved the national strategy "From patient to citizen". The plan has received praise from the Disability movement for its view that disabled people should not be seen as victims seeking help but as members of society. An important decision in the plan is the accessibility of public places and premises before 2010. Another important feature is that various authorities have been assigned special responsibility to ensure that the plan is carried out within the respective sectors.

### *Transportation service*

People who because of disablement have great difficulty in moving about or using public transport may be granted a so-called transportation service, which involves travelling by taxi or special vehicle, such as a service bus.

### *Treatment*

Many people with disabilities feel that they are met with negative attitudes and that they receive insufficient support. This is documented in a government enquiry from 1999. The State authority, Sisus, has been assigned the task of providing instruction for civil servants with a view to Improving the treatment of disabled people.

### *UN Standard Rules*

In 1993, the UN General Assembly adopted these 22 rules aimed at ensuring equal rights and liabilities, as well as full participation in society for persons with

disabilities. Although not legally binding, all signatory states have committed themselves to take action for observing them.

The Standard Rules are a cornerstone of the Swedish national action plan on disability policy approved by Parliament in the year 2000, and constitute a fundamental assessment tool for the Disability Ombudsman.

#### *Upper secondary school for students with an intellectual disability*

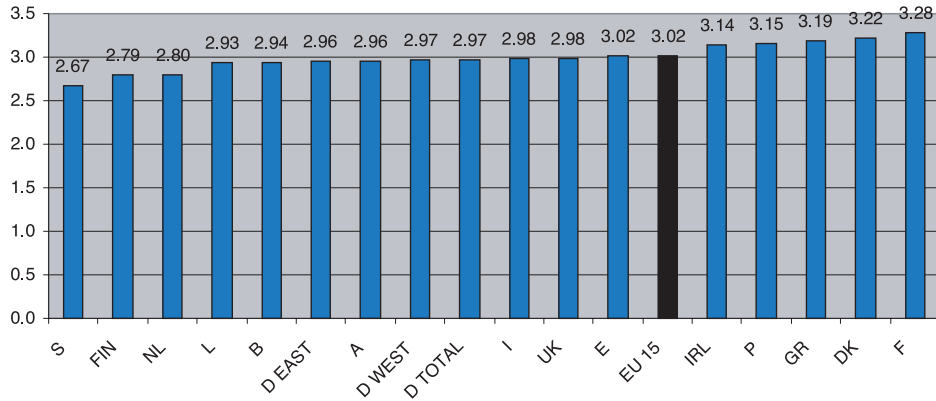
This upper secondary school is a continuation of the compulsory school for students with an intellectual disability. Like the compulsory school, it offers vocational education in national or individual programmes. Each municipality is responsible for providing young intellectually disabled with a four-year upper secondary education.

#### *Work disabled*

Persons with disability who, because of their impaired working ability find it more difficult to assert themselves in the labour market. Work disability is not a static notion. Nowadays it can, for instance, be harder to get a job if one is unable to cope with teamwork. The difficulties are linked to the demands of working life. Persons with work disability may also receive employment and a salary with special conditions in order to facilitate the working situation.

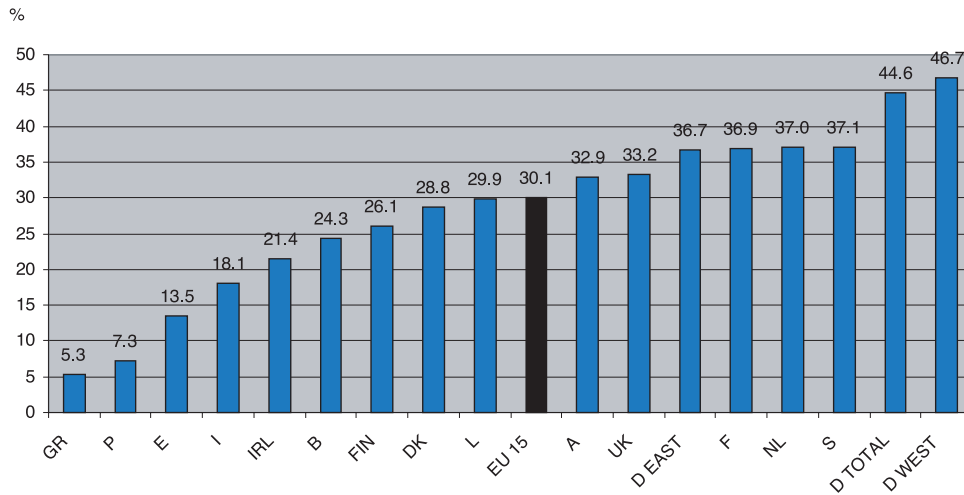
## Some facts about disabilities

"Do you think that, generally, access to restaurants, hotels, etc., is very difficult, fairly difficult, not very difficult or not at all difficult for PHYSICALLY DISABLED PEOPLE?"



Source: European Commission

Responsible for improving access: National government (In %, figures by country)



Source: European Commission

## **Sense and etiquette regarding people with disabilities**

A few simple tips – whether you have a disabled colleague, or come across a disabled person in the course of practising your profession

- When speaking to a wheelchair-borne person try to do so at the same height.
- If a disabled person is to be photographed, do it on a level with his/her eyes. This to avoid people having to stretch their necks unnecessarily, or getting a double-chin in the picture.
- Do not alter your language when talking to someone with a visual defect. It is quite OK to use words like "see", "look" and so on. The same applies when talking to someone with impaired hearing
- If you are interviewing a deaf person through sign interpretation, maintain eye contact with the deaf person, not the interpreter.
- If you interview, or work with a deaf person, take care not to conceal any part of your face.
- Never ask a person about their disability, unless it is an important part of the actual reporting, or if the person himself mentions it. It is just as inappropriate as asking people about their bald heads, obesity, or if they are divorced.
- Sometimes there is a desire to give people with a speech impediment "a helping hand" in an interview. This should not happen.
- Be prepared to repeat your questions when interviewing someone with learning difficulties. Also be prepared to give them time to formulate their answers.
- Lastly, and perhaps most importantly. If you have any questions about how you should conduct yourself or on the terms and designations to use, the simplest thing is to ask the person in question.

## **TIE3 Knowledge, Transfer and Integration Empowerment, Employability, Exploitation**

The TIE3 transnational partnership is an EQUAL initiative aimed at increasing employment opportunities for people who have difficulties in accessing the labour market .

Seven partners from six member states of the European Union take part in TIE3: Sweden, Portugal, UK, Italy, France and Spain.

Each of the partners works in different themes such as social dialogue, life-long learning, global integration models, accessibility, labour competence maintenance and recognition and gender perspective.

The participating Development Partnerships are:

Sweden	ALFA
Portugal	REQUAL
UK	EDEN
Italy	WORK
France	SOPHIA FELICIE
Spain	OSCA - INSERTA

For further information about TIE3, see website [www.tie3.org](http://www.tie3.org)

For further information about the EQUAL programme, see website <http://europa.eu.int/comm/equal>

# Paul Hansen , photographer at Dagens Nyheter, the leading daily newspaper in Sweden By Elin Gardeström

-My aim is to break with the simplistic image. I want to penetrate beyond that which is considered normal - the standardized image of what is strong and what is weak.



*Jocke Lundell*

*Photos: Paul Hansen*

Paul Hansen describes his photography of disabled people as having a snowball effect: once the work is underway it generates a continual stream of spin-offs; ideas for new visual documentaries.

Just now he is working on a reportage relating to cases of thalidomide deformity in Sweden, for which he will also write the script. But he has other fields of interest, too. For instance, the conflicts in Afghanistan and the Middle East. And recently he was in Iraq. He has received a number of awards, the latest being "Photographer of the Year" 2003, awarded by the Press Photographers' Association, for his ability to win the confidence of the people he portrays.



*Stig Abmäs*

Why did he begin photographing disabled people?

-It's not so much about the disabled as the elderly, drug-users and the homeless. In short, people on the fringe of society. The

marginalized. Hansen does not wish to enter the "realm of outsidership" as a tourist in search of the unusual and the exotic. Every journey is a venture. He tries to identify himself with his subjects.

- It's about my own insecurity. I might well have become a drug addict, had I not played such a lot of handball as a youngster. You never know. I grew up in a tough neighbourhood just outside Gothenburg.

He is often painfully aware of the similarity between himself and the people he portrays. Sometimes it is more than he can cope with.

-Many journalists and photographers tend to regard marginalized people as "them", he says, believing it to be a psychological defence; a way of distancing oneself from something distasteful. He relates indignantly how after the showing of a documentary about drug addicts, he was asked the question: "How does one get to meet one of those"?

By extension, stereotyped definitions can engender something worse. With a degree of vehemence, he quotes Roy Andersson, (a well-known Swedish film director) who said that clichés, prejudices and simplistic images are the building blocks of evil. To this Hansen adds a statement made by an official in a major newspaper about homeless people being "a sanitary liability".

For many years he worked on an evening newspaper. There it was easy enough to be a photographer, taking the simplistic pictures that recreated the stereotypes. A photographer for a tabloid newspaper, passively illustrating the version of reality that the readers are supposed to want. He describes it as going by the map instead of the real world. The meeting with Perwin Demiroglu - which led to an award-winning photo reportage - occurred at this time.

-I was driving along one day when I happened to see this woman in an electric wheelchair pushing a pram at high speed through the park. It was such a fantastic image! I drove round, stopped and spoke to her.



*Therese Thuresson with her son Linus*



*Pervin Demiroglu with her son Umut*

This was the beginning of a contact that was to last for one and a half years, and resulted in a photo reportage at his present workplace, Dagens Nyheter. The contact with Åsa Pettersson and her boyfriend Kenneth was equally random.

-I was watching a local TV programme: a documentary about a dance for disabled persons, and I thought how insensitively the television crew had represented the whole thing. A young man was interviewed and asked why he attended



*Pervin Demiroglu with her son Umut*

the dance. His reply, which took a long time since he had difficulty in getting the words out, was: "because so many strange individuals come here". A splendid answer. If anyone, it was the television people that were the strange ones in that context, which is, of course, what he meant!

Some weeks later, Paul Hansen went to a dance for disabled persons where he met Kenneth and Åsa, whose lives he followed for a period of time.

To deviate from the norm of a press photographer is quite possible and for Paul Hansen it has meant maturing as a human being. Nowadays he allows himself a lot of elbow-room, while the actual work situation remains constant. His profession entails dashing in with all his equipment to a meeting with people.

How does he handle the situation?

-You have to be yourself and respect their integrity. I usually explain very carefully why I am there, and on what terms. When I set up an arranged picture, I make it obvious to the subjects and to those who see the image that it is merely an arrangement.

Paul Hansen's basic advice to photographers (and others) is an existential one: begin with yourself and question your own prejudices. What exactly is a disability? He believes there is a powerful urge to create a we-feeling whereby disabled people are seen as "the others", who can be described by means of a simplistic image. The pitying attitude is also a simplification; and lays the responsibility elsewhere.

## Vulnerable groups lose most when the power of the state diminishes

By Christer Nilsson and Tomas Lundenmark

Sweden's leading ambassador in matters relating to the needs of disabled persons, former Minister for Health and Social Affairs Bengt Lindqvist, has left his post as the UN's Special Rapporteur on Disability after more than eight years. He has long been a leading representative of the Swedish disability movement.



Foto: Sören Andersson / Pressens Bild

At one time he was a cabinet minister in Olof Palme's government, the world's first cabinet minister with a visible disability.

During his eight years in UN service, Bengt has walked fearlessly down the paths of both democracy and oppression, armed only with his white cane as a guide. He has visited both slum districts and the corridors of established power; he has wandered with his cane and his escorts through cold, draughty institutions where the emptiness of the inmates' lives echoed in the desolate rooms.

What and how does he see on his inspection tours? The answer can be found in his reports. He sees with his experience. He sees through the eyes of others. He sees through voices that come close and whisper in confidence. He sees in the denial of those he speaks with in the government offices. He sees in the odours of neglect of people kept shut up in institutions.

He sees what he needs to see, with more acute powers of observation and greater clarity of vision than most.

It is his last day on the job as a UN official. It is 9 o'clock on a winter morning. The office he leads us into on Regeringsgatan in Stockholm is dark. Bengt makes no move to turn on the light fixture in the ceiling or the one above his desk. Why should he? He can see anyway. In the darkness it is we who are blind.

We ask him if we can turn on the light so we can make notes during our conversation.

*He summarizes his eight years in UN service for us:*

"I have had the privilege of promoting the rights of persons with disabilities with the support of an unusually good and effective UN document, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. I believe that perhaps my most important role has been to serve in an advisory and explanatory capacity in different countries. Many have said that I have been a catalyst.

NGO members have often said to me: "We never got to talk with this minister before, but now that you're here we can." Bringing parties together and getting them to talk sensibly on the basis of a UN document that serves as the foundation for a strong ideology, that has been important.

The Standard Rules are a tribute to democracy. They are very adamant on the need for strong and outspoken non-governmental organizations. It has been easy for me to work with this fine document. I have believed in every part of it."

Today Bengt will spend the day putting the finishing touches on the report from his final inspection tour. It was to Asia.

One of the countries he visited was Vietnam and its capital Hanoi, where power is centralized and the government and the parliament are located. Like many other Swedes, Bengt Lindqvist has a special relation to Vietnam after sympathy actions and demonstrations during the country's war of liberation against the USA.

*"The living standard was slightly higher than I had imagined."*

But the legacy of the communist period in the disability field lives on. Segregation is colossal and systematic. That is one of the things we will try to break up now. There are still very strict rules for collaboration. National organizations cannot be formed freely in Vietnam. They have to stand under government control, even in the disability field. The disability movement is very weak."

"But," he notes with a gesture of resignation, "that's no different than in the former Eastern European communist states. There was a very systematic segregation of people with disabilities in the entire Eastern Bloc.

Either you're productive and able-bodied. Or you're not. That was the watershed that determined people's lives in Eastern Europe – and it still does."

Disabled persons were regarded and discarded on collective grounds. They were not considered productive. Children were taken from parents so that the other members of the family could work at full capacity in production. The disabled persons were put into institutions when they were small children and stayed for the rest of their lives. The institutions were of the communist era were abominable. What is shocking is that they still exist and are just as abominable. You just have to go out into the woods in any eastern country and there they are, hidden from view.

In the Czech Republic, which is supposed to be so progressive, there are 70,000 disabled persons in institutions. Some live like cattle. I have been in 17 of these countries, and I estimate there are still at least two million people in such institutions in what we call the Eastern Bloc."

We speak about Swedish indignation at the TV programmes about Romanian orphanage children that were aired at the time of Ceausescu's fall and reflect on today's indifference in the face of similar reports.

Bengt says:

"The international attention helped that time for awhile, and lots of money poured into the orphanages. But as usual, when the spotlights dim public interest fades and people lose interest. Still, material conditions for children in general in the institutions in Romania have improved. But there are more children in the institutions today than when the stories came out in 1989. Many thousands more.

The basic problem is that parents don't have any obligations under their parental code. Parents can simply give away their children. Now they are in the process of changing the legislation, but the wheels are turning very slowly. And the children kept in the institutions for the disabled aren't even included in the discussions.

Over the past 70 years, these children have been kept out of the public eye, so Romanian society doesn't view them as being fully human. They are members of an inferior minority."

Romania is one of the countries that are negotiating for membership in the EU. Recently, ten other Eastern European countries were granted EU membership from 2004, even though most of them have a long history of oppression of disabled persons.

"Both the UN and the disability movement in Europe urged our negotiators to bring up the issue of persons with disabilities and their situation. But they didn't, since the negotiators never got the facts they needed.

Nowadays there is a fairly high awareness in the EU about the real situation for disabled persons. But the groups that are already sitting in these terrible institutions have been forgotten. They have been left out. It's a disgrace that no one talks about. The institutions are discreetly given a little money from the national budget and kept afloat in this manner.

Those who run the institutions want to run them the way they have always done. And the people who have been there all their lives don't know anything else. They can't leave the institutions. But it should be possible to make things better for them materially. I have visited institutions where the inmates don't even have clothes. They sit naked in unheated buildings."

*Bengt tells of an episode from a visit to one of these countries.*

"It was our third visit. We were at a reception with lots of people, from both the central government and regional authorities and organizations. A man came up to me and wanted to have a quiet word. He was very insistent, saying he was a doctor and it was about an institution he knew about."

He said: 'You have to bring up this institution with the state secretary when you speak to him. It's located up in the mountains and is designed for twelve intellectually disabled persons. But right now 84 persons live there and there are only two full-time attendants. The institution has no running water and it's two kilometres to the nearest well. The windows have no panes. It is very cold in the wintertime and someone always dies during the cold season. You can't let them get away with this, because they're not doing anything about it.'

Later I got a minute with the state secretary, and of course I brought this up. He replied: 'You're right. I know about this, but the problem is we have hundreds of institutions like that.' He made no attempt to cover it up. The strange thing was that the issue had not been raised before, either by the government or by the organizations of disabled persons, even though everyone was aware of it."

Bengt Lindqvist adds that fortunately we don't have these problems in Sweden. "We don't lock up disabled persons in institutions. But we have other problems we don't talk about. A great deal remains to be done when it comes to job opportunities for persons with disabilities. A law forbidding discrimination against disabled persons in the workplace recently entered into force, and we have the Employment Promotion Act from the 1970s.

But the general impression is that it is very difficult to start enforcing the new law. Perhaps I'm being unfair, but I think we're being complacent here. People say: 'We've already solved this problem.' But we haven't. I don't think either individuals or organizations, including the trade unions, are using the new law to pursue legal action with any force."

In an international perspective, the global objective of disability policy is full participation and equal opportunities. As long as there are dramatic differences in the employment rate between disabled and non-disabled persons, we can't talk about full participation.

"We are far, far behind. How far I can't say, since it has to do with how we define disability. We have to clarify whether it is enough to subjectively consider oneself to have a disability, or whether we need to have more objective criteria. But there is no doubt that the employment rate among the traditional groups of disabled persons is so low that it can only be described as a total failure. And this is in spite of the fact that by international standards, we in Sweden have pursued a very wide-ranging and ambitious labour market policy during the post-war period.

When there aren't enough jobs for everyone, market forces take over the recruitment principles. In the marketplace, the most attractive candidates get the jobs. When we wrote the Employment Promotion Act, we had a very fine ambition that recruitment in both private enterprise and government should reflect the composition of the entire labour force.

*But this has never been true.*

Every enterprise should have a greater number of persons with disabilities among its employees. When this is not the case in either private enterprise or government, you get the big differences we have today," he says.

In today's labour market it is particularly difficult for disabled persons to find jobs. Many people draw the conclusion that existing public policy instruments have missed their mark and that it is therefore time to abandon them. But Bengt doesn't agree with this.

"Instead we can say: We have got this far thanks to the instruments we have. If we want to get farther, we have to try harder. We have to confront and combat elitist recruitment principles. That's not easy. If I try to put myself in the shoes of a private employer, it's so ingrained that you choose the most attractive candidates for the job. It's very difficult to get it to work in any other way.

And how do we make persons with disabilities more attractive? This can be done to some extent by providing support, redesigning the workplace, supplying assistive devices, rehabilitation, and so on. But we can't do more than that, and if the employer is still hesitant, the choice will fall on someone without a disability. That's the way it will be as long as the law doesn't require an employer to have a certain proportion of disabled persons in relation to the size of the workforce. I don't like quotas, but it would be interesting to try."

Bengt doesn't think that the provisions of the Employment Promotion Act can be applied here either. "I would have liked to see an enforcement of the Employment Promotion Act when the labour market authorities find that an employer is flagrantly practising elite recruitment. Then they have the option of calling the employer to discussions. They should be able to demand a change in policy, and if they don't get it the last resort is to compel compliance with the law. But this has never happened, not in one single case, even though the labour market is clearly discriminatory. We didn't dare, nor did we have the political stamina. We didn't want to go so far to guarantee employment for these groups," he says with disappointment.

When the proposal for an Employment Promotion Act came, with one hundred percent backing from the disability movement, they thought that the government had finally realized what was needed. They proposed vigorous measures to bolster AMS (the Labour Market Board), with 100 new specialists for recruiting disabled persons.

"I still remember that they said that if such a specialist at AMS arranges a job for three disabled persons in a year, this would pay for his own salary. But nothing came of this."

Bengt admits that he feels frustrated when he meets his political friends and brings up issues relating to disabled persons.

"They don't say anything. I think they see me as a blue-eyed idealist. Some people like my ideas, but many think those old ideas have long ago foundered on the rocks of reality."

He still gets upset every time he reads newspaper articles or sees news reports on radio and television about conditions and living circumstances for different groups with disabilities. People with an intellectual disability are a neglected group with little hope of meaningful employment. Some municipalities that employ intellectually disabled persons in simple tasks have gone so far as to take away their day's wages of perhaps 15 kronor (a little less than 2 euro) to save money.

Bengt says: "The intellectually disabled are a group with highly varying capabilities. At the bottom of the performance ladder are those who are so severely disabled that they just can't manage any kind of organized activity. On the other hand, some kind of daily structure and meaningful activity is incredibly important even for a person with the intellectual capacity of a three-year-old. A whole scale of work activities must be available. From simple tasks to slightly more advanced tasks, then perhaps production in a sheltered workshop, and then more integrated forms of employment out in society.

Who ends up where depends on how well the system works. We can always hope that it permits the individual to progress from a lower level to more productive occupational levels. The integrated options are incredibly important, and I think a lot remains to be done there."

He has the following to say about Samhall:

"Sheltered workshops such as Samhall tend to be a mirror of problems in the open workplace. The greatest problems are people's ability to stick to a work schedule, to interact socially, to concentrate, and to have relations with other people. People who are disabled in this respect have been gathered within Samhall.

"It turns out that it isn't the blind, the deaf, the physically handicapped, but rather usually people with psychological problems and substance abuse problems."

But exclusion from the labour market is the fate of most groups with disabilities. A person with a physical disability who has been injured in a traffic accident but is otherwise still productive is hardly desirable either.

*Bengt agrees and observes:*

"Often the prospect of a job stumbles on problems with workplace accessibility. As well as on economic issues. Naturally, a workplace must be made accessible if it is not already so. We have to learn to make the workplace accessible from the start and not create barriers unnecessarily. Failure to build with accessibility in mind is a form of collective discrimination against all persons with mobility problems.

We have both a national action plan and laws to enforce this. Sweden got its first accessibility law in 1967. And yet half of the country's comprehensive schools are not wheelchair accessible. This is a disgrace. Many of our laws in the disability field are not complied with. They are not respected. This is an all-too-clear indication that the question is not being accorded any importance, and it is an affront to those of us with disabilities."

Creating greater diversity in Sweden requires vigorous action, says Bengt, and a much more active government.

"The welfare philosophy which we have had and which I advocate must form the foundation. I mean everyone's equal value and the solidarity this leads to. That we as individuals truly grant each other the right to a good life.

To manage this in a complex society such as ours requires active government. The state, which represents our collective democratic will, must pursue a policy that makes this possible. This policy must eliminate all those obstacles that stand in the way of a society with diversity and equality. The state must disseminate information and stimulate debate regarding these obstacles and take appropriate measures. We citizens must rally around and defend these principles.

The freedom of a single individual is sometimes restricted by the freedom of others, and then it is important that we recognize this and grant each other the right to a good life in fellowship with others. A strongly governed democratic state, with clear and distinct ambitions, is capable of creating a society with diversity and equality.

The government must not abdicate its responsibility. And we as citizens must become involved. We can't just turn our backs in indifference."

During the year to come, Bengt Lindqvist will have Sweden as his platform after leaving his UN post. Some work still remains to be done, and his proposals have not yet been dealt with in the appropriate UN bodies, but he will have an opportunity to become involved at home in the European Year of People with Disabilities.

He is very happy about the choice of theme for the Year of People with Disabilities in Sweden – Human Rights. "I have worked with human rights as a UN rapporteur. And the big thing that has happened in the past four years is that we have had an international breakthrough for the view of the disability issue as one of human rights."

*This is how he describes this breakthrough:*

The UN's Universal Declaration of Human Rights was written with all human beings in mind, but the disability aspect was forgotten. Talk of discrimination and segregation was exclusively concerned with discrimination on the basis of race, religion or gender.

This neglect of the disability dimension has since continued. None of the big conventions based on the Universal Declaration of Human Rights – with civil and political rights on the one hand and economic, social and cultural rights on the other – mention the disability dimension. You could say that the whole sense of exclusion experienced by disabled people has not been regarded as a human rights violation, but merely as a natural consequence of being disabled."

The disability dimension continued to be neglected in all the big conventions that are based on the Universal Declaration of Human Rights.

We in the disability movement objected to this. It was important to include this dimension. During the Year of Disabled Persons which the UN proclaimed back in 1981, we demanded that the UN recognize discrimination against disabled persons. This was not done immediately, but the following year a passage was included in a World Programme of Action Concerning Disabled Persons that was written as a consequence of the Year of Disabled Persons.

The formulation stated that the relationship between disability and human rights should be studied. But now, 20 years later, a definitive breakthrough has finally arrived. The UN is in complete agreement that a disability dimension must be built into its monitoring of human rights."

The question is currently being investigated. But the Commission on Human Rights brought up the issue of disability in all three of the years 1998, 2000 and 2002. A very definite standpoint has been taken that disability is the responsibility of the UN's Commission on Human Rights, that we must build a disability dimension into all monitoring.

The breakthrough also led to a proposal for a special convention on the rights of persons with disabilities. "This work has just begun," notes Bengt Lindqvist. The fact that the disability dimension is now included as a human right is the clearest proof of the success achieved by the UN's Special Rapporteur.

But success hasn't come easily. Discrimination against persons with disabilities is nothing anybody wants to admit responsibility for. According to Bengt Lindqvist, the rights of people with disabilities are violated every day.

"These are direct violations which may be concerned with inadequate care, self-determination, personal integrity, etc. But also the right to education. Only a fraction of persons with disabilities have an education. And this is precisely the same type of rights violation and discrimination that occurs on other grounds. It is also the reason why I suggested to the Commission on Attitudes towards Persons with Disabilities (otherwise known as the "Lindqvist nine") that we

should amend the Swedish Constitution and recognize disability as one of the dimensions.

There has long been a well-intentioned recognition of the fact that human rights also apply to persons with disabilities. But when it comes down to individual cases, it is no longer a question of human rights. Then it is a question of resources, or that something has been overlooked in the planning," he says critically.

All the time there is an alienation, an isolation caused by discriminatory acts against persons with disabilities. This is primarily due to ignorance, or the attitude that the disability movement is asking for the impossible.

"We are told that discriminatory forms of treatment should not be regarded as human rights violations. To that I reply that the blind have never demanded to be able to enjoy Rembrandt's paintings, since we know that we can't see them. But we do demand to be able to read the same newspapers as others read, because that is possible. And if we don't get to do that, it's a huge violation of our rights," he says.

When Bengt Lindqvist compares the Swedish perspective on disability issues with the international one, he sees several differences.

"Nordic disability policy is a part of our overall welfare policy. We have built up paratransit services and home help services and assistive technology services on the basis of common sense.

In the Anglo-Saxon systems, especially in the USA, they work from the opposite direction. Based on a human rights perspective they try to compel progress by taking legal action against those responsible – usually the state.

The question of which approach works best is one of political judgement. We base our system on solidarity. This has given our disability policy a much greater breadth than, for example, in the USA. Their system favours strong individuals who are capable of advocating their cause. And of course there is something very appealing in that way of looking at things, in "knowing you're right."

But most disabled persons don't have the resources needed for effective litigation and advocacy. So I think our system is better.

But we obviously don't believe that ourselves, since we are increasingly changing our way of doing things to suit the rules of the market economy. The more we allow the market to rule, by deregulating and reducing the power of the state, the more vulnerable our groups will become."

The growing demand for antidiscrimination laws in Sweden has a lot to do with this general trend. There is a connection between what is happening in society at large and the ability of vulnerable groups to assert their rights. Bengt Lindqvist believes that this ability is steadily being undermined as a consequence of the shift in the political tides.

"The current political trend to deregulate and privatize puts weak groups, those who are dependent on public solidarity to be able to live a decent life, at greater risk. If this solidarity is undermined, their position will be weakened. Strong individuals – whether they are persons with disabilities, immigrants or women – will manage anyway."

During his travels, Bengt Lindqvist has had occasion to observe a broad gap between the bold rhetoric of politicians and the actual living conditions of the weak groups in society.

"This gap exists all over the world. Why it is bigger for persons with disabilities than for many other groups, I don't know. It may have to do with the fact that no one wants to be seen as making things worse for persons with disabilities. Spokesmen for the political parties claim that they are all in agreement on the disability issue. "We all want what's best." Then some of them go home and deregulate and lower taxes. Which undermines the state's ability to give support to weak and vulnerable groups.

On one side of the table are those who hold the purse strings. They are expected to follow laws and rules. On the other side are we, persons with disabilities. We are fighting for extremely important things in our lives. We have a picture in our minds of what we are entitled to. This picture is the result of what we have read and heard. We know our rights because politicians have told us what they are. We also speak among ourselves and know what rights others have who are in the same situation. And we perceive a huge gap between what the politicians say and our own reality.

You may wonder how that gap can be bridged? As an activist on the disabled side of the table, I can demand that the politicians keep their promises in terms of support, services, assistance and aid. This is only reasonable.

We are told that there isn't enough money. The politicians try to play one group against another. It's a classic tactic of divide and conquer," he says with indignation.

For him it is a question of income distribution. And as long as some people are wallowing in affluence while others are living in poverty, which isn't acceptable here in Sweden, there is good reason to think about income redistribution.

"Many people who happen to have disabilities are victims of unfair treatment from the viewpoint of income distribution. We are not the only ones who are unfairly treated. But when we are excluded from essential things in life, we must have the right to demand a fairer distribution of income. We must forge alliances with other vulnerable groups to stop the politicians from playing us against each other."

Bengt envisions cooperation with other groups who fight for the interests of their members, such as immigrant groups and women's groups, and deplors the lack of such cooperation today.

"But attempts have been made to create it. The disability movement has actually proposed formation of a solidarity group, which existed briefly in the 1990s but didn't last.

Something that was really fun to be a part of happened in 1979–80. A number of NGOs decided to conduct a joint analysis of where we stood in the question of welfare. We wrote a white book where we described the ongoing dismantlement of our welfare. The white book became an important issue in the 1982 election. I was chairman of the group and I probably owe my election to Parliament in 1982 to this work with the white book. We could benefit from this kind of cooperation now too.

We would definitely have benefited from it during the 1990s, which were difficult years. It was then our political leaders assured us that the weak groups in society would not suffer. Nevertheless, when social support systems are dismantled we know that they are the ones who bear the brunt of it."

To the question of why the disability movement hasn't taken stronger action, he replies:

"The representatives of the disability movement find it very difficult to make themselves heard above today's media buzz. They do the best they can. But what they need to do is to get the attention of journalists, whose mission is to keep an eye on the authorities on behalf of their readers, to get them to take an interest in disabled persons' stories.

Perhaps I'm a bit paranoid, but I have the feeling that the power elite is keeping the lid on things. It's a little unsettling. No one really wants to get to the bottom of this question."

Bengt Lindqvist is disappointed in the policy that has been pursued since he left the Government in the early 1990s. "I can't deny it. I'm disappointed in the fact that the Government no longer gives the same weight to their income distribution policy. There isn't a single political party that is actively pursuing an ideologically based debate on income distribution. They sporadically focus on the needs of different groups from time to time. And that's good. But nothing is done about it. No one proposes any solutions. Many of us think it's high time for a debate on income distribution policy.

The gap between rich and poor is growing. Are we really just going to accept that? Is it an automatic consequence of globalization? Or do we find ourselves in a position where we have lost control? This is something we need to discuss.

There is a risk that deviant groups will be marginalized. Those who have had to pay the price of the liberalization that occurred when both neoliberalism and the economic crisis coincided in time are the weak groups in society. If deregulation and decentralization, which in themselves are positive phenomena, are mismanaged, the consequences can be devastating for vulnerable groups. When the power of the state and its policies is weakened, they are the real losers.

This is easy to understand, since the weak groups are the ones who are most dependent on public support.

As a blind person, I couldn't live a decent life without a strong public sector. I would have to struggle to scrape by on charity. Either in a brutal form or in more sophisticated forms. And I think it's bad that such aspects haven't been brought out more clearly in the debate.

I agree with those who say that today the elite is on a collision course with the Swedish people. The elite control the media, they control politics and they control industry."

He sees a widening of the value gap as a growing danger. The elite don't seem to have anything against lining their own pockets and making more and more money. The rest of the people, who are loyal to the system, are struggling. Caught in the middle are the real losers, those who are most dependent on local government programmes.

"I am very critical of this trend. Globalization must never be an excuse for the absence of an active income distribution policy. Otherwise, the vulnerable groups in society will be the big losers. I hope that the European Year of People with Disabilities will focus on these issues in such a way that we put a stop to violations of the human rights of people with disabilities in Sweden," says Bengt Lindqvist. The global society's view of people with disabilities will become manifest in the continued work with Bengt Lindqvist's proposal to the UN General Assembly.

The proposal for new wordings has now been summarized in a supplement. Bengt has chosen not to propose a revision of the Standard Rules from 1993 for fear of watering down the document.

"But we have produced a strong supplement. It is so strong that there is a clear risk it won't be adopted. There is already a tendency towards this. The proposal is currently under consideration by the Commission for Social Development and should have been circulated for comment. But the Secretariat is dragging its feet."

The Commission for Social Development will make a decision on the supplement after the review procedure, before it proceeds to the UN General Assembly. If the Commission doesn't reject it entirely because it is politically impossible, it will come up on the General Assembly's agenda some time during 2004.

"Let's hope so," says Bengt, who has made a reputation for himself as the blind Swede who has tried through his work to open the eyes of the world's politicians.

*This chapter is an extract of the book *Tänk själv* (Think for Yourself). Commercial copying and use are forbidden. *Tänk själv* is a product of EQUAL and Paraplyprojektet.*

