



Nordic Centre for Welfare and Social Issues



Focus on

NORDIC DISABILITY POLICIES

Preface

The focus of this publication is on policy for the disabled in the Nordic countries. One of the objectives of the Nordic Centre for Welfare and Social Issues (NVC) is to provide knowledge and insight and to provoke debate, and that is also the purpose of this document - and of all our publications.

The initiative for this publication came originally from the Sixth Network of the Nordic Disability Policy Council, whose members work to coordinate disability policies within government bodies. The publication contains facts about the Nordic countries' policies in this area, topical articles, interviews with users and politicians, presentation of research on disability and a glance at the international scene. If you want to know more, examine our recommendations for literature and relevant links.

In this theme publication we highlight the achievements made in Nordic disability policy, but also areas which need further attention. We also make various recommendations which we hope will contribute to achieving the high goals common to the Nordic countries: namely the full inclusion of persons with disabilities within society.

NVC recommends that:

- An increased Nordic cooperation is supported nationally in order to coordinate national collaboration on the UN Convention. The Nordic countries can also use a common Nordic profile at Conferences for States Parties to the UN and within the EU.
- Labour market policy aims to facilitate diversity and to allow more persons with disabilities to enter working life or to retain their present employment. Job coaches have proved to yield good results. It is a matter of stimulating and lowering the thresholds for vulnerable groups in order to reduce exclusion from working life. This relates to young people, disabled people, immigrants and older people. Better cooperation between schools/educational institutions and working life is needed.
- Lacking or unsatisfactory accessibility to environments, goods and services and to information technology should be evidence of discrimination.
- Universal design should be the basis for all societal planning, whether central, regional and in the municipalities - in both public and private sectors.
- User organisations should be granted space and representation in the decision process at different levels, centrally, regionally and in the municipalities.
- Disability research should be granted the resources and freedom to generate new knowledge of use to the involved worker groups in various sectors of society, and also useful for developing disability policy.

Enjoy your reading! Enjoy your debates!

Tone Mørk
Director NVC



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Executive editor and publisher:
Director Tone Mørk
Edited by: Louise Hertzberg

Editorial team:
Gerd Vidje
Helena Lagercrantz
Ingemar Oderstedt
Lasse Winter Wehner
Magnus Gudnason
Louise Hertzberg
Martina Harrikari

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Nordic Centre for Welfare and Social Issues

Sweden
Box 22028
104 22 Stockholm
Sweden
Visitors' address:
Hantverkargatan 29
Tel: +46-8-545 536 00
info@nordicwelfare.org

Nordic Centre for Welfare and Social Issues

Finland
Annegatan 29 A 23
FIN-00100 Helsinki
Finland
Tel: +358-9-694 8082
nvcfi@nordicwelfare.org

Nordic Centre for Welfare and Social Issues

Denmark
Slotsgade 8
DK-9330 Dronninglund
Denmark
Tel: +45 96 47 16 00
nvcdk@nordicwelfare.org



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Nordic Centre for Welfare and Social Issues



1

CHAPTER

Equality, parity and full participation in society for all persons - this is the fundamental value of Nordic and national disability policy. Such is its formulation in national disability policy programs and in Nordic disability policy collaboration.

Nordic disability policy rests on two pillars: the general welfare policy of universalism, and specific measures such as disability aids and personal assistance.

The Nordic countries have incorporated disability policy in their government programs, and cooperation in Nordic disability policy has existed for some 30 years. The Nordic Council on Disability Policy, with its mandate from the Nordic coordinating ministries to create policies and provide advice, has played an active role since 1997.

Input from the Nordic countries to UN decision-making and policy documents has made a significant impression in recent decades. The UN's World Programme of Action in the seventies is an early example. The view that disability issues are a matter of human rights has won more and more ground. "From patient to fellow-citizen" and the human rights perspective sum up this paradigm shift. The UN's Standard Rules and the later UN Convention on the rights of persons with disabilities of December 2006 reflect in their preambles the values underlying disability policy in the Nordic countries. The construction of these instruments, with a supervisory function, monitoring committee and special reports was put into practice by the UN with Nordic support. Today's state conferences, at which UN member countries follow up the UN Convention and submit national

reports, show that disability policy has achieved an international foothold and a place on the political agenda.

Norwegian Member of Parliament Karin Andersen points out the paradigm shift. The UN Convention "represents a new direction and a new logic, a completely new approach as a basis for equality and antidiscrimination policies."

Among the Nordic countries, Sweden and Denmark have ratified the UN Convention. Other countries are working on the ratification process, which it is anticipated will be followed by implementation and monitoring/supervision. User organisations are following developments closely and are working for the introduction of a national supervisory function. The UN's supervisory committee needs to be enlarged, for example with Nordic representation. It is also important nationally and locally to provide clear information on the consequences of a ratified convention at various levels of society. In these processes countries can learn from each other by exchange of experiences and can evaluate successful models.

NVC recommends that increased Nordic cooperation is supported nationally in order to coordinate national cooperation on the UN Convention. The

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tion. The first cohort of students has now graduated. Similar courses are available in Dublin, Ireland, and in Lund, Sweden, with links to university and technical colleges. A common obstacle is that young people are not provided with sufficient stimulation in their basic education. This obstacle must be eliminated, in order to increase further education opportunities and give young people a better start in life.

Inadequate accessibility is evidence of discrimination in the Norwegian anti-discrimination legislation.

NVC recommends that lacking or unsatisfactory accessibility to environments, goods and services and to information technology, should be evidence of discrimination.

NVC recommends that design for all/universal design is made fundamental to all societal planning whether central, regional or in the municipalities. This applies alike to public and private activities, to contracts and to other purchasing.

The focus of this theme publication on Nordic disability policy reflects interaction between lawmaker/state, regions, municipalities and the disability movements. Legislation is a fine thing, but it is not enough. "Laws and regulations need to function as a constant reminder that all development of activities addressed to the general public must employ universal design. This principle must be included right from the planning stage," emphasises Inge Ovesen of the Norwegian Ministry of Children, Equality and Social Inclusion. She continues: "The policy interest organisations receive NOK 150 million per year for their work.

That is a large sum and shows how important their critical voice and participation are."

The disability organisations represent those who "know where the shoe pinches". It is also the disability organisations, many of them founded at the end of the 19th century alongside other popular movements, who in their fight for decent living conditions have given substance to today's disability policies. Inclusion is not just a politically popular idea: it requires the translation of values and policies into practical form. User participation is another term which implies that disability organisations must be given space and influence in the decision-making process at various levels.

NVC recommends that the user-organisations are given the relevant space and representation in decision processes at various levels, whether centrally, regionally or in the municipalities.

The task of the professional staffs of the support and service organisations in the Nordic countries is not just to apply regulations but also to realise disability policy in daily life through stimulation and knowledge transfer and creative solutions. More can be done, locally, nationally and at Nordic level, not least in respect of support, stimulation and knowledge transfer to the relevant worker groups.

NVC recommends that disability research receives resources and freedom to generate new knowledge of use to the relevant worker groups in the different social sectors and also useful at the Nordic level for the development of disability policy.

Facts



2

CHAPTER



Nordic disability policies

The Nordic countries are regarded as among the world leaders in respect of disability policy. This was evident during the negotiations for the UN Convention on the rights of disabled people, where representatives from the Nordic countries were very active.

The Convention stipulates that disabled persons must be fully included in society. There is nothing new in this. It is completely in line with the changing views which have more and more imposed themselves internationally. Previously a medical view held sway. The starting point was the individual and what prevented him or her from fully participating in society. This view also had a built-in acceptance that disabled persons often do not have the same opportunities as other people, are dependent on other people looking after them and have limited opportunities for being active in society.

Since the 1970's this perspective has altered with the adoption of the social view.¹. Instead of starting from the individual, societal weaknesses came into focus. What is it about society which means that disabled persons have limited opportunities and are excluded? What needs to be changed in society to bring about full inclusion?

In the present UN Convention on disabled persons' rights, the starting point is the same - creating a society in which disabled persons participate on an equal footing with everyone else. With

the coming of the Convention, the pressure for change will be that much greater. Creating a society for all is not just desirable. States which ratify the convention commit themselves to creating such a society. The transition is from a social view to human rights thinking. The Nordic countries are very positive about the UN Convention and support its ideology.

Nordic welfare model

No country in the world can boast that it has fulfilled the whole of the UN Convention, but the Nordic countries are in many ways well-placed. In 2005 Professor Stefán Ólafsson of the University of Iceland published the book *Disability and Welfare in Iceland in an International Comparison*². In this book he concludes that the Scandinavian welfare model, applied in varying forms in the Nordic countries³, offers the best basis for ensuring that disabled persons do not fall behind others in living standards and enjoy opportunities for being included in society. Ólafsson says that what he described in 2005 is still the case now in 2010.

The differences between the three main welfare models he describes as follows:

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1. The Union of the Physically Impaired Against Segregation (UPIAS), founded in 1976 in the UK, was the driving force here.
2. Órorka og velferð á Íslandi og í öðrum vestrænum löndum
3. With regard to Iceland, Ólafsson considers the country to have the Scandinavian model as an aim, but the book reports that Iceland differs in a number of ways. There is less redistribution of income, but greater participation in working life.

WELFARE MODEL	American	Germanic	Scandinavian
Role of government	small	considerable	large
Role of social security	limited	extensive	extensive
Pensioners' living standard	low	depends on social class	high
Social welfare services	limited	limited	extensive
Poverty level	high	considerable	low
Income equalisation	limited	considerable	extensive
Sexual equality	limited	limited	extensive
Reduction of differences between social classes	limited	limited	extensive

In general the Scandinavian model involves the state taking a wide responsibility for equalising life chances between people. Services are usually universal, in other words, they are provided regardless of the contribution of the individual. This means that in the Nordic countries there are ample opportunities for ensuring that disabled persons do not fall behind in living standards and for participating in social life.

Professors Rune Halvorsen and Bjorn Hvinden write about Nordic disability policies in the recently published anthology *Funksjons-hemming – politikk, hverdagsliv og arbeidsliv*. In an article *Nordic policies for the disabled encounter international equality policies* they conclude, just as Ólafsson does, that the Nordic welfare model gives a good basis, but even so they consider that it has many weaknesses.

According to Hvinden and Halvorsen, the following is what the public authorities can be expected to achieve:

- *That disabled persons who require supplemental income receive it, that the level is relatively high and that the amounts received are predictable.*

- *That measures are taken to help disabled persons to work on the ordinary labour market. This involves both including those left outside and helping those already in employment to remain there.*
- *That disabled persons receive sufficient social services to enable them to live independently and to manage their life both practically and financially. Alternatively that these persons receive the financial support to secure these services on their own.*
- *That systematic efforts are made to make goods, services and buildings accessible to all, including by laying down requirements for public transport, design of buildings and information and communications technology.*
- *That disability policies are coordinated to ensure harmony between the different public initiatives.*

This then is the expectation. But how well does it match with reality? Hvinden and Halvorsen's analysis shows variable results.

The Nordic countries have achieved relatively good results in respect of income redistribution.

Comparing the Nordic countries with the rest of Europe, there is a lower proportion of disabled persons living in relative poverty (poor in relation to the country's general standard of living).

But on the labour market the situation is by no means as successful. For persons with severe disabilities, the employment level in the Nordic countries lies between 28 and 63 per cent⁴. The figures are uncertain, but there are no indications that the Nordic countries are at the forefront here.

With regard to social services which permit an independent life, the Nordic countries have concentrated relatively more on services than on direct financial support than is the case in the rest of Europe. For example, in all Nordic countries there is the availability of personal assistance to enable persons with severe disabilities to be included in society and to function in daily life.

The Nordic countries have also undergone a trend towards general public services which are also useable by the disabled. This could be described as a normalisation, whereby special institutions for the disabled disappear. However, this trend is not equally clear for all groups of disabled persons. Hvinden and Halvorsen write that Norway and Sweden allow a higher degree of inclusion for persons with learning difficulties or mental illness in their general services than is the case in Finland and Denmark.

More accessibility needed

With regard to accessibility, the Nordic countries are not among the leaders. Hvinden and Halvorsen write that the available statistics show that many European cities are more accessible for persons with restricted movement than the Nordic capitals. It also appears that

the Nordic countries lag behind when it comes to available and useable information and communications technology, according to Hvinden and Halvorsen. With regard to the coordination of disability policies, Hvinden and Halvorsen write that Nordic disability policy is characterised by cooperation and trust.

They feel that the lack of progress in working life is due to the fact that so much is determined between the trade unions and employers organisations. Neither of these parties has forced the pace to allow disabled persons to get a job. The interest of trade unions has often been limited to those already in employment who become disabled.

Confidence in the political system also means that the authorities have greater scope of action than in countries with different political traditions. This has led to the Nordic authorities having great power and wide elbow-room for their own interpretation of what disabled persons are entitled to.

So, compared to countries with the Anglo-Saxon system, there are far fewer opportunities for individuals to appeal decisions. Hvinden and Halvorsen make a comparison with Ireland, where there are appeal bodies for persons who feel themselves discriminated against. A commission for human rights has been set up with strong powers to supervise Ireland's compliance with its human rights obligations.

The culture of trust and cooperation which has characterised the Nordic model has changed slightly since the mid 1990's, and this change will probably continue in the future. Since the mid 1990's, directives and regulations have been

4. One study shows that Denmark is lowest with 28 per cent employment. In another study, Norway is lowest with 44 per cent, Sweden and Finland are higher at around 50–60 per cent. The European average is around 40 per cent.

introduced within the EU to protect the rights of disabled persons in working life and to lay down requirements for improvements in accessibility. This has led to more legally binding rules which the EU countries have undertaken to follow.

The UN Convention, signed by all the Nordic countries and so far (June 2010) ratified by Sweden and Denmark, is also a legally binding document which lays down requirements for reform.

Development of human rights approach

Work is ongoing to develop a human rights approach, one where persons with disabilities may make demands based on legal rights which they possess as individuals.

The Nordic region has a high acceptance of the UN Convention and its perspective, but there is also criticism of a more prominent human rights approach. A trend towards more judicial testing is seen by some as a step away from the Nordic model, characterised as it is by cooperation. There is an unease that this will lead to businesses becoming less cooperative and more likely to protect themselves from control and demands for judicial testing.

Critics hold that this weakens democratic influence and that power will flow from elected politicians to the courts. Some also feel that this type of judicial testing matches a liberal market economy viewpoint, with the individual at the centre. This has no place in the solidaristic welfare policy typical of the Nordic model.

Those who welcome the change see greater opportunities for enabling individuals to secure their interests by legal means. They also consider that it gives greater scope for disabled persons and their organisations to participate in and influence the development of welfare policy.

Finally, Hvinden and Halvorsen write that the change to more judicial testing is a challenge and requires care to prevent unreasonable demands on business in creating accessibility and providing work opportunities. At the same time the two researchers believe that the Nordic countries are agreed that society must take a large responsibility for the costs, and that business will therefore be compensated.



LEGISLATION

The Nordic countries have laws and other guidance documents intended to protect disabled persons from discrimination and to guarantee an inclusive society. The following describes the important laws and normative documents as they currently appear.

Finland

Since 2000, anti-discrimination has been incorporated in the Finnish constitution. Together with the Finnish Equal Opportunities Act, the Constitution guarantees the non-discrimination of disabled citizens. The Equal Opportunities Act came into force in 2004. According to the law, authorities are obliged to make determined and structured efforts to promote equal opportunities in all societal functions and if necessary to change circumstances in which equal opportunities are not being achieved.

Sweden

Under the Swedish "Regeringsform", one of the four Swedish constitutional documents, it is stated that the public authorities must act to ensure that all persons are able to participate on an equal footing in society. The authorities must combat discrimination of persons on account of disability.

There is no general law in Sweden as there is in Finland. In Sweden the emphasis is on the sectoral responsibility for ensuring that disability policy is promoted in all areas of society. This is regulated in the Statutory Instrument on the national authorities' responsibility for implementing disability policy⁵. The Statutory Instrument states that authorities must act to ensure that all persons with disability are allowed full participation in society and parity of living conditions.

In 1999 Sweden introduced a ban on discrimination in working life. The provisions of this law have now been incorporated in the law of 2009 which consolidated all the

discrimination legislation. For disabled persons, as well as protection from discrimination in working life, there is also protection against discrimination as regards education in technical colleges and universities. At the time of writing, there are also political moves to get Sweden to legislate that inadequate accessibility is discrimination.

Norway

In Norway there are no disability rights enshrined in the constitution, but in 1994 a supplement to the constitution was made which states that it is the duty of the national authorities to respect and secure human rights. The Norwegian Human Rights Act has since 2008 named the disabled among those to be protected against hate crimes.

In 2009 the Norwegian Discrimination and Accessibility Act came into force. The law covers all areas of society. It is so far unique in the Nordic region, in that inadequate accessibility is regarded as discrimination and that those who infringe this provision may be required to pay damages by the state. The ban covers not only public buildings but also private buildings meant for public use, such as shops and restaurants.

Denmark

The Danish constitution contains no mention of disabled persons. Instead an important document is the Danish Parliament's policy decision of 1993 that all national and local authorities and private enterprises and organisations must comply with the principle that disabled persons are to be treated equally to other citizens

5. Statutory Instrument 2001:526

and must have the same rights and opportunities as other citizens. Denmark has no general legislation on disabled persons. The emphasis is on sectoral responsibility, such that in every area of society the principles of Danish disability policy must be applied. There are laws which affect disabled persons, such as active labour market measures, social services and social benefits such as the early retirement scheme.

Iceland

In 1980 Iceland adopted a law on persons with learning difficulties. The aim of this law was to make it possible for disabled persons to live as normal a life as others do. This law is seen as a milestone. It broke with the earlier view which was mostly about care and protection. An important part of the law was thus that the disability organisations were guaranteed a voice in the design of the services promised in the Act. Subsequently the law has been extended to cover all with a disability.

Norway and Sweden

Norway and Sweden have discrimination ombudsmen, who supervise compliance with the anti-discrimination laws. Sweden formerly had a disability ombudsman, but the tasks in this post were transferred to the general discrimination ombudsman, or DO, in 2009. In Sweden the discrimination ombudsman, the DO, may take cases to court, but the usual course is a voluntary agreement between the DO and the party suspected of discrimination. In Norway, cases go in the first instance to the Equality and Discrimination Ombud, the LDO. If no agreement can be reached, the case is decided by the Equality and Discrimination Board, which has the power to levy fines for proven discrimination.

OTHER CONTROL INSTRUMENTS

Alongside legislation, strategic disability policy documents have an important function in policy-making.

Norway

The Norwegian government's strategy document "From user to citizen - a strategy for bringing down the barriers for the disabled 2001" contains a comprehensive discussion of the effect of legislation on policies. Reference is made to research showing that financial, social and political contexts have great significance for the successful application of laws. It is hard to achieve results by relying on legislation alone (NOU 2001:22).

When this strategy document was written, Norwegian legislation was not at all characterised by a rights approach. However it can be seen as the starting point for the rights approach current in Norway now.

Now another document has had a strong influence on Norwegian disability policy. This is a vision for a universally designed Norway by the year 2025. Four areas have been prioritised: information and communications technology (ICT), urban and outdoor planning, buildings and transport. The vision is that most people must be able to use these functions without needing special solutions.

Sweden

The Swedish national action plan of 2000 has almost the same name as the Norwegian "From user to citizen". It is called "From patient to citizen". The Swedish plan had three main goals:

- Social cohesion based on diversity
- That society be so designed that

disabled people of all ages can achieve full participation in social life.

- Parity of living conditions, for women and men, girls and boys, with disabilities.

There was also talk of Sweden being accessible by 2010.

Three areas were prioritised in the plan:

- Individual solutions to problems
- Accessible public transport
- Accessible government administration

Much has been done, but much remains to be done. This year, 2010, the government has confirmed that the overall goals of the plan are still valid and that a strategy will be drawn up for realising it fully.

Finland

With the aim of strengthening the rights of disabled persons, the government of Finland intends to produce a disability policy programme to be ready by 2010.

The programme is based on the first Finnish disability policy report, presented to the Finnish Parliament in 2006⁶, and on the UN Convention for persons with disabilities and its optional protocol relating to a system for individual appeals. The new disability policy programme will be drawn up in consultation with various administrative areas and expert bodies.

Iceland

In Iceland an action plan for the period 2007 -2016 has been drawn up. The basis for the action plan came about with support from working parties consisting of representatives from the disability organisations and social service staff. The plan is divided into the following areas:

- Services for children 0–17 years and their parents
- Housing services
- Support for work and training/ rehabilitation.
- Support for those of 18 years and older.
- Users' situation and influence
- Attitude work
- Quality work
- Knowledge resources - resources of personnel and structure

Iceland has also drawn up a separate plan for persons with long-term mental illness, as it was concluded that their needs would not be met by the general action plan. Before drawing up the plan, separate studies were made of housing, work and daily activities, to see how a policy could be framed which encouraged an independent life and greater participation in society. The action plan "Services for people with psychiatric disability" lasted for the years 2006-2010 and has now been implemented.

Denmark

In 2003 the Danish Parliament adopted a national disability plan. The government paper "Action plan for the disability area" described a number of major focus areas, including housing, leisure and life quality, work and training and physical accessibility.

6. Cabinet report on disability policy 2006, Ministry of Social Affairs and Health 2006:10 (Finland)



UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

There are likely to be many amendments to laws and guidance documents to ensure that the countries can live up to the requirements of the UN Convention on the rights of persons with disabilities.

The UN Convention on the rights of persons with disabilities was adopted by the UN General Assembly in 2006. The Convention involves a clear shift of perspective on persons with disability: from seeing such persons as “objects” of charity, medical treatment or social protection, to seeing them as

“subjects” with rights. In the new convention, the starting point is that disabled people are capable of taking decisions about their own lives and of being active citizens within society.

The Convention has 50 articles and a supplementary (optional) protocol, which allows recourse to

the advisory committee once all legal avenues have been exhausted in the individual countries.⁷

The Chairman of the Ad Hoc Committee which negotiated the UN Convention on the rights of persons with disabilities, New Zealand UN Ambassador Don MacKay, has made it clear that if international agreements in the disabilities area conflict with the new UN Convention, the UN Convention will take precedence.

Denmark, Finland, Norway and Sweden all played an important role in the negotiations which led to the Convention. In some cases Norway was able to act as a bridge-builder between the EU and other players and countries. Denmark, Finland and Sweden were active within the EU group.

All the Nordic countries signed the convention at the first opportunity, on 30 March 2007. Two of the Nordic countries have ratified the convention, Sweden doing so on 15 December 2008 and Denmark on 24 July 2009.

Sweden and Denmark

In 2008, Sweden set up an inquiry to examine how far Swedish legislation and other circumstances in Sweden meet the requirements of the convention and its protocol. A reference group including representatives of the disability movement was linked to the head of the inquiry. The inquiry's conclusion was that there were no obstacles to Sweden's ratification of the convention, and the government accordingly requested Parliament to ratify both the convention and the supplementary protocol⁸.

A separate inquiry on how to apply Convention article 33, par. 2, was also set up⁹. Article 33, par. 2, relates to which authorities are to have overall responsibility for promoting, safeguarding and

monitoring the convention. The inquiry proposed that the main responsibility for promoting, safeguarding and monitoring the convention should lie with the Discrimination Ombudsman, the DO, but that Handisam should continue to be responsible for promotion in areas prioritised by the government and primarily involving to authorities, municipalities and counties. A government bill is expected in 2010.

States which have ratified the UN Convention must submit reports to a supervisory committee. One important task of the committee is to interpret the convention and to make sure that member states comply with it. In January 2011 Sweden is due to submit its report to the UN supervisory committee on Sweden's efforts to implement the convention and the results obtained. The Swedish disability movement has advised that it plans to produce a shadow report. Denmark will submit its first report in summer 2011.

From autumn 2010 the Convention's monitoring committee will be increased from 12 to 18 members. One important task of the committee is to interpret the convention and to make sure that member states comply with it. Sweden or Denmark may be able to have a representative on the expanded committee subject to cooperation.

Denmark

Before Denmark ratified the convention a broad process was carried out to determine the conditions for ratification and the consequences the decision would have. The then Welfare Ministry acted as disability coordination ministry and appointed a cross-ministerial working group to

7. in English: www.un.org/disabilities/default.asp?navid=13&pid=150 and in Swedish www.sweden.gov.se/content/1/c6/12/36/15/618de295.pdf
8. www.sweden.gov.se/sb/d/108/a/101918
9. www.sweden.gov.se/sb/d/108/a/126637

analyse the situation.

The group concluded that apart from the change already effected to the electoral law, no further amendments to legislation were needed to permit ratification. The group's findings were presented to the government in March 2009 and were the basis for the proposal to ratify the convention.

Three other groups studied the issues of accessibility, education and anti-discrimination provisions in order to acquire an understanding of what would be needed in the gradual implementation of the convention's principles.

Just as in Sweden, Denmark had to decide how to comply with the demands for promotion, safeguarding and monitoring of compliance with the convention set out in Article 33, Par. 2.

A cross-ministerial group of senior officers under the leadership of the Social Affairs Ministry has been tasked with identifying a national framework for organising work on promoting, safeguarding and monitoring in Denmark. In its work the group started from the existing institutions. On the basis of the group's report, the government has decided that the main work of promoting, safeguarding and monitoring will be undertaken by the Institute for Human Rights. In addition the Central Disability Council will play an important role in performing the tasks of Convention Article 33, Par. 2.

Norway

It is hoped that Norway will be able to ratify the convention within the near future. The Norwegian authorities consider that an amendment to guardianship legislation needs to be made first. This law has now been drafted but will only come into force when the budgetary backing for a new

guardianship administration is in place. Attention has now turned to the law on the right to goods and services, which also needs amendment. In 2009 the Act for prohibition of discrimination on the grounds of disability came into force. This law was also a necessary condition for Norway's ratification of the Convention.

Finland

Finland anticipates ratification at the start of the next government period in 2011–2015. Amendments to the law on municipal residence and laws limiting the right to self-determination are under consideration in the Ministry of Social Affairs and Health. The convention will be ratified after the necessary amendments to the legislation have been made.

Iceland

In February 2008 Iceland's Social Affairs Ministry appointed a committee to investigate what would be necessary to allow Iceland to ratify the convention. The group included representatives from various ministries and disability organisations. The group has examined and analysed the changes needed and has concluded that the legislation for services and aid needs amending.

The legal amendments are expected to be completed in 2010. They are necessary not just for ratifying the convention but also to transfer responsibility for services and aid from the state to the municipalities. This change will also mean the municipalities taking on a high degree of responsibility for the gradual implementation of the convention.

EU

EU has signed the convention. This was done in March 2007.

DEFINITION OF DISABILITY

Article 1 of the UN Convention on the rights of persons with disabilities contains the definition that "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

The question of definition was the subject of extensive discussion during the negotiations in New York. It was finally agreed that it would be left to the member states to decide in detail which disabilities should be included. One important argument was that the idea of disability changes over time.

Part of the discussion centred on which words should be used to translate the English word "disability". In the Swedish translation of the Convention the words *funktionsnedsättning* and *funktionshinder* (functional impairment and functional hindrances) were used. The Swedish National Board of Health and Welfare gives the following guidance on interpreting these terms:

- Functional impairment is now defined as an impairment of physical, mental or intellectual functional capacity.
- Functional hindrances are seen as the limitations which a functional impairment causes a person in relation to their surroundings.

Norway has had a similar debate and in a report of 2001¹⁰ the same definitions were proposed as used in Sweden.

Of equal interest to the actual terms are the arguments for modes of expression. Whichever term is chosen, there is a common Nordic view that disability arises as an interaction between the individual's function and conditions presupposed in the surrounding

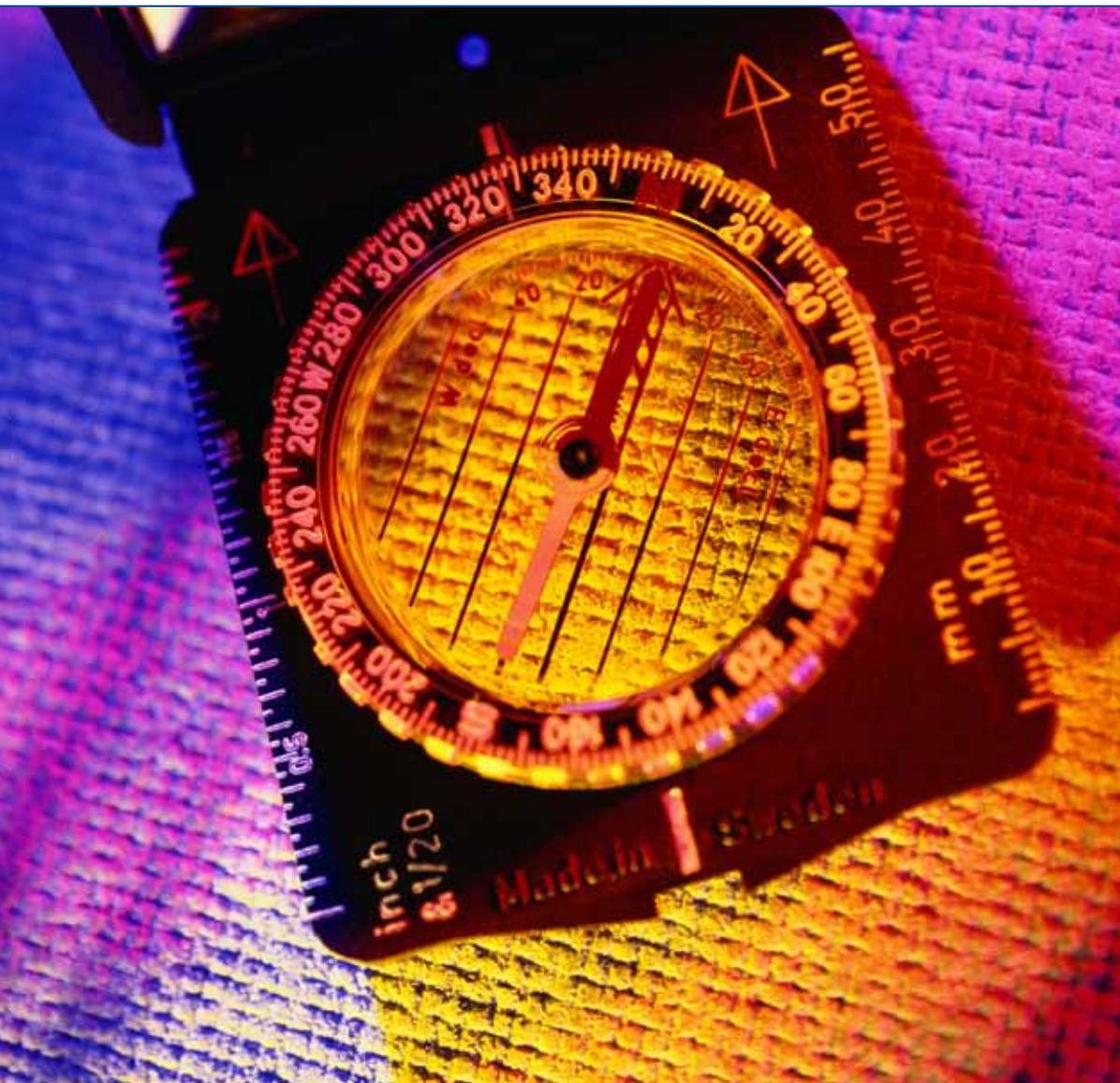
world. This also chimes with the view of the UN Convention.

This perspective is also present in the UN's Standard Rules of 1993. For example the standard rules contain this description of the significance of environment:

"Both the causes and the consequences of disability vary throughout the world. Those variations are the result of different socio-economic circumstances and of the different provisions that States make for the well-being of their citizens".¹¹

The World Health Organisation WHO has adopted a classification called ICF (International Classification of Functioning) in which state of health, disorder or disease are located in a dynamic system together with other functions such as body functions and structures, activity and participation. ICF can be seen as a way of capturing the interaction between individuals and their environment. ICF is finding increasing use, but it also has its critics, not least because it is regarded as having a far too medical approach and because it is unclear whether it really captures the relationship between individual and environment or merely points to the individual's limitations.¹²

10. Mannåkerutvalget NOU 2001:22
 11. Background and current needs Par. 2
 12. <http://www.who.int/classifications/icf/en/>



COORDINATION

Disability policy covers a wide number of areas of social life, includes many players and is very complex. The need for coordination is consequently very great.

The Nordic countries have chosen various models of coordination.

In four countries (Denmark, Finland, Iceland and Sweden) the Social Affairs Ministry or similar has a coordinating role within government. In Norway, the Ministry of Children, Equality and Social Inclusion has this role. The Norwegian solution shows that disability issues are not primarily a social or medical issue.

Finland

In Finland the Social Affairs and Health Ministry is responsible for coordinating disability policy. Connected to the Ministry of Social Affairs and Health is the nationwide disability council VANE, which is a cooperative body for authorities, disability organisations and relatives organisations. The task of the Council is to assist in the development of society, to act to improve

the living conditions of disabled persons and to work for the realisation of human rights for persons with disabilities.

The Institute for Health and Welfare (THL), a research and development institute within the Social Affairs and Health Ministry's administrative area, is also involved in the promotion of disability policy through annual agreements with the Ministry.

All administrative areas are responsible for disability policy activities according to the sectoral responsibility principle. The national administration takes the lead and acts as advisor to local authorities and the private sector in this work. The main sectoral responsibility lies with players with responsibility for building, planning and the environment, traffic and communication, education, workforce, culture, social affairs, health and housing.

Sweden

In Sweden the Ministry of Social Affairs is responsible for coordinating disability policy. Sweden has a disability delegation, led by the Cabinet and responsible for disability issues. There is also an inter-ministerial working party.

In conjunction with the introduction of the national action plan for disability policy in 2000, 14 authorities were given a special sectoral responsibility for implementing general disability policy goals. The authority for disability policy coordination, Handisam, was established in 2006, one of its tasks being to support the national authorities in implementing the national action plan. Handisam is a staff authority reporting directly to the government.

Denmark

Denmark has a cross-ministerial committee of senior officials with

representatives from all Ministries. Work is coordinated by the Social Affairs Ministry, which also has a secretariat function. The council meets at least three times a year and representatives of the disability organisations are invited to attend. There is also a series of ad hoc groups set up whenever close coordination is required between ministries. For example, such groups were created ahead of the ratification of the UN Convention.

There is also a central council, DCH, The Danish Disability Council, with representatives from users and authorities. Since the start, the Council has striven to spread the view that disability issues should be seen as areas of social responsibility. The objective of DCH is to help create a society with equal opportunities for disabled persons.

The Danish Disability Council has a double function:

- to advise the public authorities
- to provide a representative voice in the application of rules, laws and practice relating to disability.

The Danish Disability Council works closely with the Equal Opportunities Centre for Disabled Persons, CLH, which is the secretariat for the Disability Council.

CLH, established in 1993, is an independent state institution under the Ministry of Social Affairs. As a guarantee of its independence, the board is composed of equal numbers of representatives from disability organisations and the authorities. The Centre has no authority of its own, but exerts influence through the documentation and disclosure of areas in which disabled person do not enjoy the same opportunities as others. CLH also has the task of following international development and linking them to developments in Denmark.

Norway

Norway has a Council of Senior Officials which coordinates the country's disability policies. The Ministry of Children, Equality and Social Inclusion has the overall responsibility and accommodates the secretariat for the Council of Senior Officials. The government practises the principle of sectoral responsibility. This means that all ministries with subordinate authorities must draw up strategies and provisions for disabled persons. This applies, for example, to the Labour and Welfare Service, the Health Directorate, the Education and Training Directorate, the Children, Youth and Family Affairs Directorate, municipalities and disability aids centres.

Iceland

In Iceland, all questions relating to services for disabled persons are within the purview of the Minister of Social Affairs and Social Security. In addition the Minister for Social Affairs and Social Security has access to an advisory committee with representatives from the two national disability organisations. The committee also includes a representative from the National Association of Municipalities.

The work of the committee includes providing proposals to the Minister regarding services at national level and administering the fund which finances projects, especially those relating to property linked with services to disabled persons. The committee is comparable with a Senior Officials Group at national level.

Apart from the national administration, Iceland is divided into eight service regions. Each of these has a regional council with representatives from the region's municipalities and the national disability organisations and representatives selected by the Minister of Social

Affairs and Social Security.

The regional councils have existed since 1980 when the first law on persons with learning difficulties was passed.

The task of the regional councils is to provide proposals for services for disabled persons within the region, and to implement the national regional office's service proposals and financial plans.

Another important task for the regional councils is to monitor that disabled persons are receiving what they are entitled to, both with regard to general social services and care and to services specifically directed to the disabled. Among other matters, the councils must handle complaints from disabled persons and their relatives.

Each council also elects a person from its region to look after the interests of the relevant persons. This person works in concert with the council. This is an important supervisory function.

The level of activity of the councils has varied, but in the main the Social Affairs and Social Security Ministry considers that the role of the councils in submitting proposals and examining cases has contributed to the establishment and implementation of the service.

The regional councils have been reduced in number, from eight to six. In the two former regions and in certain smaller areas, the municipalities have taken over responsibility for services for disabled children and adults.

A radical reform of the whole system has been commenced and from January 2011 the intention is that the responsibility for services will be transferred from the state and regions to the municipalities.



MAJOR PUBLIC PLAYERS

Overall policies are administered at national level but there is also political responsibility at regional and municipal level.

Denmark

Denmark implemented a major municipal reform in 2007 in which the number of municipalities was reduced from 271 to 98. There are also five regions responsible for healthcare. These replace 13 former counties. One of the aims of the reform was to give the municipalities greater responsibility and to transfer a greater number of political decisions to local level, in

order to strengthen democracy. The Danish municipalities have a central position in providing services and support to disabled people.

Norway

Norway's 430 municipalities and 19 regions (county authorities) have an important role as local/regional decision-makers and social service providers. The municipalities are

responsible for areas such as children's welfare, care of the elderly and primary and lower secondary education. The counties are responsible for further education (further vocational training and higher education) and local transport.

Iceland

Iceland currently has six state-administered care and service districts and five municipalities or municipal groupings which have taken over services for disabled children and adults. From 2011 it is intended that the municipalities will take over full responsibility for this field. The aim is to bring decisions closer to individual citizens.

Finland

At the start of 2010 Finland had 342 municipalities and 184 joint municipalities, corresponding to Sweden's municipal consortia for cooperation in specific task areas. So for instance there are 13 joint municipalities for specialist care.

The number of municipalities is due to go down. A wave of municipal mergers has rolled through the land, following a government decision to reform the municipalities. The municipalities have been directed by central government to:

- secure a vital, active and unified municipal structure.
- strengthen cooperation in the provision of services.

Sweden

Sweden underwent a similar process in the 60's and 70's, and today has 290 municipalities with a high level of responsibility for disabled persons. Health issues and public transport are administered by Sweden's 19 county councils and two regions.

All Nordic countries have professional and coordinating organisations for municipalities and coun-

ties.

Municipalities and Counties of Sweden (SKL) is an employers and professional body for municipalities and counties. SKL looks after the interests of municipalities and counties and offers them support and services. SKL has a great significance for the development of welfare for the elderly and disabled persons in Sweden.

Denmark

The corresponding body in Denmark is called Local Government Denmark (KL) and has a similar role to SKL in Sweden.

Norway

Norway has KS, or Municipal Sector's Professional and Employers Organisation, for the Norwegian municipalities and counties.

Finland

Finland has two organisations: Finnish Municipal Alliance which looks after the interests of the municipalities. There is also the Municipal Labour Market Department, KA, which is the employers organisation for the municipal sector.

Iceland

Iceland has a national association of all the country's 78 municipalities. This association is a professional organisation which provides various types of support, advice and other services to the individual municipalities. The association is also the employers organisation and negotiates with trades unions with employees in the municipal field.

There are also regional municipal associations in eight regions. These are primarily professional organisations, while the individual municipalities handle the actual employer function.

DISABILITY COUNCILS

At local and regional level, representatives of the disabled exert influence via disability councils.

Finland

In Finland there are disability councils in approximately half the municipalities. The councils are generally consultation bodies for municipal decisions. Councils are usually set up by local or municipal administrations, but the initiative can come from municipal committees, disability organisations or individual residents. Disability councils should contain representatives of local residents with disabilities and their relatives, representatives of the local disability organisations and municipal officials and shop stewards. Councils generally have 6-10 members.

Sweden

Almost all municipalities in Sweden have a disability council. They act as consultation bodies for disability issues. This means that municipal committees and administration must send important cases from a disabilities point of view for comments or consideration by the council. Most councils are linked to a committee or municipal administration. The persons represented on the council vary. Often they include representatives from disability organisations, politicians and officials. There are also councils which are more dominated by municipal officers.

Denmark

Denmark introduced a law on municipal disability councils in April 2006. The councils must consist of equal numbers of user representatives and politicians. Council members are chosen from disability organisations and municipal administrations. A municipal

administration is obliged to consult the disability council in all questions of relevance to disabled people. A study by the Social Affairs Ministry has shown that the great majority of those who sit on disability councils see this as giving them the opportunity to comment on significant cases and feel that their views are respected.

Norway

In Norway municipal and regional disability councils have been a legal obligation since 2007. The constitution of the councils may vary, but it is important that representatives of disability organisations are included and determine how the councils work. The councils are seen as important for developing local democracy and for systematically hearing users' experiences so that inclusive solutions can be selected from the start instead of making special provision afterwards.

Iceland

Iceland has no equivalent to the handicap councils as most services are provided by the state. To a certain extent the regional councils cover this function. In the larger municipalities and districts there are national disability organisations which act as representatives for disabled children and adults.

CENTRALISED/DECENTRALISED SUPPORT FOR DISABLED PERSONS

The Nordic countries vary a good deal in their degree of decentralisation, i.e. how much is administered directly in municipalities and regions and how much is handled at central level.

With regard to the payment of financial compensation linked to disabilities, this is mainly financed by money collected by the state, for example via taxes on employees and employers. This system applies to all Nordic countries.

The state also handles the actual payment. The exception to this is Denmark, where administration is performed by the municipalities. In Denmark the municipalities do not receive full compensation from the state for payments made, but also contribute with municipal financing.

As regards the financing of day-to-day social services and care, this is usually handled in the Nordic region at local level. But here too the state has an influence as a proportion of the money comes from state contributions. In Denmark and Sweden the state contribution is lowest and is provided for general services. Finland and Iceland have the highest proportion of state financing and here there is also a high degree of control over what the contributions may be used for. As regards non day-to-day services, the countries vary. For example, in the case of job provision:

In all Nordic countries except Denmark there are national employment services which also support disabled persons. In Denmark the responsibility for

support and job provision has been transferred to the municipalities. Disability aids provision is an area where there are notable differences between the countries:

In Denmark, the municipalities are responsible for aids.

In Finland the state contributes to financing of disability aids, but responsibility lies with the municipalities, which decide independently how to organise their service to the public.

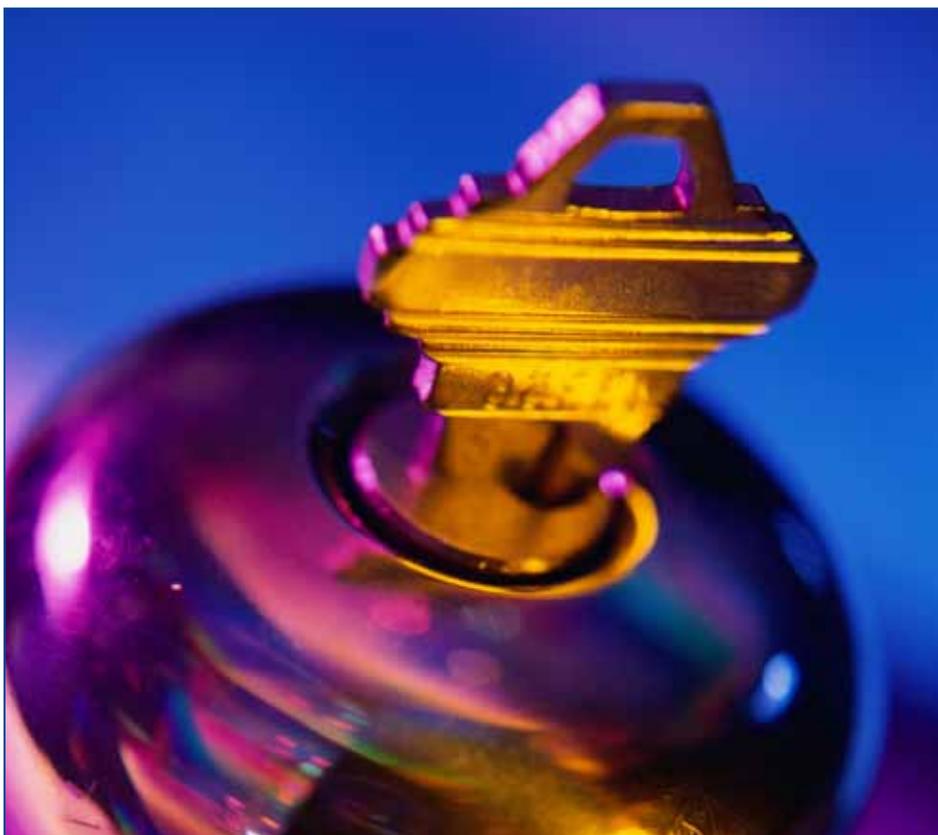
In Iceland the state has traditionally been responsible for disability aids provision, but this will presumably change from 2011.

Disability aids in Norway are mainly financed by the state, but several players are involved in disability aid provision. The municipalities are responsible for rehabilitation, and disability aids provision is seen as part of rehabilitation.

Municipalities and counties in Sweden are responsible for disability aids provision. In the case of work aids, the two national authorities Swedish Public Employment Services and Social Insurance are responsible for financing.

In conclusion it is hard to make a hard and fast division between centralised and decentralised administration. There is some of both, but a very rough breakdown of the countries is shown in the figure below.

Centralised	Both centralised and decentralised	Decentralised
	Norway	
		Denmark
	Finland	
	Sweden	
Iceland		(Iceland presumably from 2011)



DISABILITY ORGANISATIONS

The Nordic countries are characterised by well-organised user movements. Apart from individual organisations, often organised by diagnosis or type of disability, there are large umbrella organisations whose main work is as lobbyists.

The following umbrella organisations exist in the Nordic countries:

Denmark

In Denmark the disability organisations are organised within Danish Disability Organisations, DH, formerly called DSI. DH has 32 member organisations and works on general disability policy issues affecting the member organisations. DH has 97 municipal branches.¹³

Norway

FFO (Joint Organisation of the Disabled) with 70 member organisations is Norway's biggest umbrella organisation for persons with a disability or chronic illness. FFO's

main goals are equality and participation in society, and to improve the quality of everyday life for persons with a disability or chronic illness. FFO also hopes to create arenas in which member organisations can meet and discuss common interests. FFO is represented at regional level, in all counties and in many municipalities. FFO was established in 1950¹⁴.

SAFO (Cooperative Forum of Organisations for the Disabled) is a relatively new cooperative forum for three disability organisations in Norway, the objective of which is to make a difference through participation in the political process and in cooperation with other organisations and other environments.

13. www.handicap.dk

14. www.ffo.no

15. www.safo.no

16. www.hso.se

17. www.obi.is

18. www.throskahjalp.is

19. www.sosteryty.fi

20. www.handikappforbundet.fi

SAFO has existed since 1995.¹⁵

Sweden

The Disability Alliance Cooperative Body, HSO, is an umbrella organisation consisting of some 40 disability associations. Its task is to be a unified voice for the disability movement with respect to government, parliament and central authorities. HSO is also present in counties and municipalities. These work independently from the national body.¹⁶

Five organisations in Sweden have recently established the organisation Lika Unika (Equal Unique). The focus of the new organisation is human rights. Lika Unika believes that disability issues are no longer just about welfare but also about human rights. This therefore means finding new ways to make a difference and new ways of working.

Iceland

Icelandic Disability Association (ÖBÍ) is one of Iceland's two umbrella organisations. It has 34 member organisations, all with representation on the board. Apart from its lobbying work, it is also active in advice-giving and cooperation with authorities over jobs for disabled people. ÖBÍ's member associations consist primarily of the disabled themselves (e.g. persons with physical disabilities and serious chronic disabling illnesses).¹⁷

The other umbrella organisation, Landssamtökin Þroskahjálp (Na-

tional Association for Support and Development)¹⁸, has 22 member associations, most being parents and support associations for children and young people with mental disabilities. There are also associations for professionals, such as the social workers' association. Þroskahjálp also carries on lobbying work and cooperates with public authorities on issues relating to disability.

Finland

The biggest umbrella organisation in Finland is YTY, Sosiaali- ja terveystyöjärjestöjen yhteistyöyhdistys¹⁹, the Social Care and Health Organisations Cooperative Association. YTY has 133 member organisations, many representing disability organisations, but there are also organisations working on issues affecting children, the elderly, alcohol problems etc.

Finlands Svenska Handikappförbundet or Swedish Disabled Alliance of Finland is the umbrella organisation for organisations active among the Swedish-language population of Finland.²⁰

At the Nordic level there is the Nordic Council of the Disability Movement (HNR), in which umbrella organisations and other disability organisations from the whole Nordic Region are represented. HNR makes up one third of The Nordic Council on Disability Policy. HNR receives financial support from the Nordic Council of Ministers via a support scheme under the Nordic Centre for Welfare and Social Issues.



PRIVATE PLAYERS

Certain services, rehabilitation and training which have traditionally been regarded as a public responsibility are today being provided by private enterprise.

For example, Sweden has passed the Act on the Freedom of Choice System (LOV). Those municipalities which wish to do so may allow persons with disabilities to decide for themselves where their support and care services come from - they may either stay with the municipality or select a private contractor.²¹

In a somewhat similar fashion, Denmark has recently introduced "service certificates" for persons entitled to practical and personal help (home help). Users are then able to employ their own help or allow a private company to perform the service. This facility also exists in Finland and it is intended to extend the system to cover areas other than just help in the home.

In 2009 Denmark also introduced the idea of user-controlled personal assistance. This means that persons with disabilities whose needs are such that they require personal assistance may turn to an organisation, relative or private company to have these services provided.

In all the other Nordic countries there are similar opportunities for those whose disabilities are so severe that they are entitled to personal assistance.

Alongside increasing openness to provision of services from private sources, the number of private players is also on the way up. In Sweden, for example, there are at least 450 businesses, charities and organisations offering personal assistants.

Some of the biggest players are user cooperatives inspired by the Independent Living Movement in the USA.

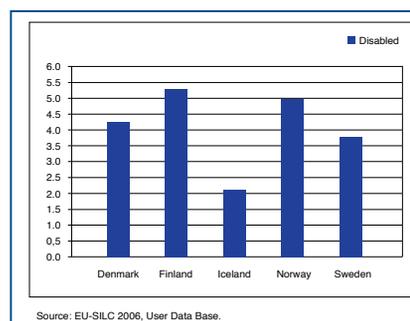
STATISTICS AND INDICATORS

Statistics and indicators are important instruments for following up the work of improving rights and living conditions for disabled persons and for permitting comparisons of conditions across different countries.

One method of comparison is to note the percentage of GNP (Gross National Product) devoted to disabled persons. The latest statistics are from 2007²²:

Denmark	4,2
Finland	3,1
Iceland	2,8
Norway	4,2
Sweden	4,4

The percentage of disabled people in the population can be hard to determine. Different definitions are used in different contexts and countries. NOSOSKO, the Nordic Social Statistics Committee, has done some work based on self-reporting by interviewees. Those who regard themselves as disabled or were incapable of work at the time of the interview and had had no income in the previous year. See figure below:



The definition can of course be discussed, but a clear advantage compared to other measures is that it produces comparable data. This has previously been a deficiency.

21. www.sweden.gov.se/sb/d/108/a/99454
 22. Source: Nomesco/Nososco Database

Nordic disability policy cooperation

Nordic cooperation within the disability area has been taking place in various organisational forms since the 1980's, mainly through a Nordic institution, for example NNH, the Nordic Committees for Disability Issues or NSH, the Nordic Cooperative Body for Disability Issues. Mandate and tasks originated from the Nordic Council of Ministers, NMR. For example it was early noted how useful Nordic cooperation was in the smaller and less well known disability groups. In 2009 the institution Nordic Centre for Welfare and Social Issues, NVC, has come on the scene, handling disability issues alongside other focus areas in the welfare policy spectrum. NVC is an institution under the Nordic Council of Ministers/Ministries of Social Affairs and Health.

The Nordic Council on Disability Policy

The Nordic Council on Disability Policy is an advisory and policy-forming body for the Nordic Council of Ministers, NMR. The council was established in 1997 and takes its mandate from the Nordic cooperating ministries.

Design for all as concept and strategy was part of the council's first platform in 1997, and is still a fundamental principle in the Council's outreach activities.

The Council exists to promote Nordic cooperation in disability issues within all relevant areas of society and to contribute to the realisation of common Nordic disability policy goals for equality and full participation in society.

The Council's work aims to support the implementation of the sectoral responsibility principle in the Nordic Council of Ministers.

The UN Convention on the rights of persons with disabilities (De-

ember 2006) is normative for the Council's work. Its implementation in the Nordic countries is supervised by the Council.

The Council's 20 members include parliamentarians and representatives of the disability organisations, various specialist ministries and the autonomous regions.

The secretariat function is performed by the Nordic Centre for Welfare and Social Issues, NVC. The Council's work is financed by separate funding from the Nordic Council of Ministers.

Part of the Council's policy-forming outreach consists in declarations and input at the political level to the relevant national ministers, for example, newly identified challenges or obstacles or opportunities within disability policy - say on accessible public transport or theatre and culture for all, whether as stage crew, performers or spectators. Museums for all has been a focus area during the first decade of this century. The city for all is another example.

The advisory function to the Nordic Council of Ministers requires that the Council actively intervenes as soon as possible in administrative and political processes. In this function the Council is also a consultation body for the NMR.

Network organisation

Linked to the Council are six networks with members from the Nordic countries' government offices and autonomous regions. The main idea is both to keep close to the political level and to develop specialist skills in the sectors and thus contribute to the Council's activities. The networks may also execute decisions or take up project assignments from the Council, and, according to mandate, undertake projects or investigations on their own initiative.

The network organisation

consists of five sectoral networks within social planning and building issues, culture, transport, the labour market and education. A sixth network consists of members from the ministries with a national disability policy coordination function. Altogether some thirty national Nordic ministries are included in the networks.

Policy-forming activities which have emerged from the networks include conferences, specific projects and declarations to relevant ministers. The present document is itself the result of an initiative from the Council's sixth network.

Nordic Centre for Welfare and Social Issues

The task of the Nordic Centre for Welfare and Social Issues is to improve quality in the social policy field in the Nordic region through education, information, promotion of research, development work, network building and international cooperation. One of its focus areas is initiating and developing cooperative projects which can improve the situation of disabled persons. Great emphasis is placed on cooperation with the international disability movements and on development work in the Nordic border regions. Within the area of deaf-blindness, the institution operates courses, development and documentation work. The overarching aim is to improve the quality of work in the field. Knowledge is also made available to relevant occupational groups in other areas.

International commitments

The Nordic countries play an important role in international cooperation.

The majority of the global disability organisations have been chaired by persons from the Nordic countries: Kalle Könkkölä at Disabled People's International

(DPI), Liisa Kauppinen and Markku Jokinen at World Federation of the Deaf (WFD), Stig Ohlsson and Lex Grandia at World Federation of Deafblind (WFDB), Kicki Nordström at World Blind Union (WBU) and Jan-Peter Strömgren at International Federation for Hard of Hearing People (IFHOH).

Karl Back Jensen has been co-chair of the World Federation of Users and Survivors of Psychiatry (WNUSP).

Liisa Kauppinen, Kicki Nordström and Jan-Peter Strömgren have been chairs of IDA (International Disability Alliance) – the global umbrella organisation for disabled people.

Certain of the global disability organisations have or have had a secretariat in the Nordic Region: WFD in Finland, WFDB in Sweden and Denmark and World Network of Users and Survivors of Psychiatry (WNUSP) in Denmark.

Development authorities in the Nordic countries support projects and other initiatives for disabled persons.

In Denmark, Finland, Norway and Sweden the disability movements have aid organisations. Persons from the Nordic disability movements are also active in European cooperation, e.g. within EDF – European Disability Forum.

Certain Nordic EU parliamentarians have participated actively in the Disability Intergroup within the EU Parliament.





3

CHAPTER

From real life



A lot of exciting things are happening in all the Nordic countries in the field of disability policies. All of them are making progress, though in different areas. There is a lot we can learn from each other. In this chapter, we will be discussing, among other things, the law in Norway that classes lack of accessibility as discrimination, university education in Iceland for people with disabilities, the entitlement of people with a speech impairment in Finland to an interpreter, advanced advisory services in Denmark, and how Sweden has made great strides in creating culture for everyone, irrespective of their functional capacity.

In the Vasa Museum's experience room, all children can take part, irrespective of functional capacity.

1 NVC recommends

2 Facts

3 From real life

4 Policy

5 From users

6 From research

7 International overview

8 Useful information

9 Summary

A new challenge for culture

It is impossible to imagine culture without creativity. More and more cultural workers are now beginning to use their creativity to make culture available to everyone. The Vasa Museum in Stockholm is running a project that should inspire the cultural world to think in a new, broad and different way.

The Vasa Museum in Stockholm attracts visitors from all over the world. This is not surprising. The ship that sank on its maiden voyage almost 400 years ago (1628) was not only one of the largest warships of the time. It was also an art treasure. The ship is alive with figures depicting Roman warriors, fair mermaids, angry lions and Greek gods. The ship and its interior stimulate the imagination of children and adults alike. It

is in this spirit of creativity and imagination that project manager Carina Ostenfeldt appears to have been working with the “All Aboard!” project – the salutogenic museum. The visible result at the Vasa Museum is a room at the museum that offers a total experience for all the senses – regardless of functional capacity.

“When a class of schoolchildren is due to visit, the teacher doesn’t need to ask whether we have adapted things for children with this or that special need. This is really for all children,” says Carina Ostenfeldt.

Carina Ostenfeldt invites us into the room – or, to put it more accurately, invites us to place our hand into a lion’s mouth so the door opens and we can board. We are now aboard. Here, we can choose to stop where we are or head off onto the deck or the bridge. To get there, you go in a diving-bell. This is an example of success using broad, inclusive solutions rather than thinking in terms of adaptations.

“If you have a lift for wheelchair users, it becomes a special solution. Well, the diving-bell is a lift and this therefore becomes the way everyone travels up. The democratic solution should also be

Julia Hedenström is one of the group of children engaged by the Vasa Museum as experts.



the most attractive one.”

This is the thinking running through everything in the room. Nothing is a special solution for a special group. Another example is when the children get to try to steer the ship. In just the same way as the person steering the Vasa ship was unable to see where the ship was heading, the children today have to ask their pals for help so they know the ship is moving correctly.

“It makes no difference whether you are visually impaired or not. It’s the same for everyone,” says Carina Ostenfeldt.

No ready-made solutions

Carina Ostenfeldt receives many enquiries from museums and elsewhere seeking specific advice on how to find comparable solutions. But she does not have any available.

“It’s like life in general. There are no ready-made checklists that fit universally. They need to be developed according to the situation. In the same context that the problems arise, you can also find the solution to the situation,” she says, smiling.

Instead, the aim of the project is to spread the mode of thinking, a philosophy of accessibility.

It is about regarding it as an issue about democracy and human rights, and something that is important to health, too. This is why we talk of the salutogenic (health-promoting) perspective.

“All people have a right to be part of a context. The activity should be organised in such a way that it is intelligible, manageable and meaningful whatever your starting position.

This requires broad, inclusive and liberating solutions. To find these solutions, a person should not be sitting in an office working things out. Rather, it is about having a learning process for the whole of the organisation, where the thoughts and ideas of many

Facts

The Vasa Museum project is supported by the Swedish Inheritance Fund and is a collaboration between the Swedish national maritime museums, the Swedish National Association for Disabled Children and Youths (RBU) in Stockholm County, Save the Children Sweden, the Astrid Lindgren Children’s Hospital at the Karolinska University Hospital, the Swedish National Agency for Special Needs Education and Schools and Handisam (the Swedish Agency for Disability Policy Coordination). Carina Ostenfeldt is in charge of ideas and concepts. www.allaombord.se

Two mobile units, called Vipers, are located at the Astrid Lindgren Children’s Hospitals at Huddinge and Solna. The units contain material for therapeutic play, discovery and training, with the Vasa ship as the theme. This makes the museum an active part of the rehabilitation chain for children and young people.

UN convention

The UN convention on the rights of persons with disabilities Article 30 Participation in cultural life, recreation, leisure and sport.

Article 30 stipulates that countries must take measures to ensure that disabled people are able to participate in cultural life on equal terms with everyone else.

3

From
real life



people lead to clever solutions. From the outset, an expert group consisting of children from the Swedish National Association for Disabled Children and Youths (RBU) was engaged on the project. The children have been given posts and are remunerated just like anyone else on the project.

“They are doubly qualified as they are both children and have a disability. They can overrule my steering groups if there is something which they think will not be right.

The lecturers also have an important role to play as they are the ones who take care of the groups who visit the museum. They have to be involved in developing the activity so that it addresses all the senses and is rich in offers and challenges.”

Thousands of lectures

There has been a great deal of interest in the concept on which the project is based. Since the room opened in the autumn of 2008, Carina Ostenfeldt has held lectures and received study visits no fewer than 5,000 times. She sees that both as a good sign and as proof that there is still much that remains to be done.

“There is a dawning of interest in this method of working, but there is still a long way to go before this culture is accessible to everyone. Otherwise, this would not have been arousing such a great deal of attention. But things are going in the right direction.”

Siv Junback, who is an official at the Swedish Arts Council, has also

been along to the Vasa Museum. She is finding that a lot of positive things are happening in the cultural sector, and that there is a shift from special solutions to ones where the solutions are designed from the outset to suit everyone.

“From the authority’s side, we removed the special subsidies for accessibility, as we found that it was resulting in collateral projects. On the other hand, I do believe that, when you work in an inclusive way, you need to be prepared for it to cost more, and this is something I think we should be able to support.

“I agree with Carina that we need this way of thinking throughout the whole organisation. But we can’t have an “accessibility person” who thinks about accessibility while everyone else carries on working as normal. We need to be part of a context. The work on accessibility needs to be linked to the various activities. Put simply, there needs to be more than one of us.”

Wine at break time

Siv Junback explains that more and more proposals are coming from cultural institutions. She mentions the City Museum and Backa Theatre in Gothenburg as examples of organisations where all staff have been urged to look at things from an accessibility perspective.

“It is not just about there being a toilet that can be used if you use a powered wheelchair. We also need to make sure that the person sitting in the powered wheelchair has the opportunity to have a glass



of wine in his or her break times, just like everyone else.”

The Swedish Arts Council is one of a total of 14 sectoral authorities. These 14 have special responsibility for ensuring that the disability policy goals are achieved.

“We have to be a supportive, unifying and promoting force within the area of culture. I believe our work has had some effect. Simply by asking questions we have got cultural workers to take note of the issue.”

Siv Junback explains that it was the library where people first worked on accessibility. Now, the performing arts are showing an interest.

“The first stage was to put on some performances that everyone could watch. Now there are more and more inclusive performances which allow disabled people to be on stage, too. But this does require some work. It isn’t always possible to get onto the stage at all,” says Siv Junback.

Courage to face life and curiosity

At the same time, the cultural sector is a world that is constantly facing new challenges, where creativity is an important part of the job. This means the conditions are particularly good. Carina Ostenfeldt believes there is no alternative to solving the problems.

“I think there should be zero tolerance to lack of accessibility in activities aimed at children and young people. In those cases, the UN Convention on the rights of children must apply.”

There are solutions, and this is her starting point. This is what is stated in the explanation of the All Aboard project programme:

“It is about attitudes, curiosity about new solutions, diversity instead of simplicity, and a certain measure of courage to face life and creativity to face new challenges and create meaning in this.”

The Nordic Council on Disability Policy

During the past decade, The Nordic Council on Disability Policy has been running ongoing projects about “museums for all”, with Nordic inspirational conferences for museum managers and their staff, the dissemination of information to museum employees, and the setting up of a digital information and dialogue forum (www.cultureforall.info, cultureforall@accessibility-lists.info).

Furthermore, through its cultural network the Council has presented two declarations to the Nordic cultural ministers:

- The Hallunda declaration on accessible performing arts (2007), which was aimed at ensuring that it was possible for disabled people to work behind and on the stage, and to attend as part of the audience without any impediment.
- The Reykjavik declaration on visibility within the media and in the various expressions of culture, and in its arenas (2009). The declaration was aimed at getting away from the “victim or hero role” as reflected in the media, and at concentrating cultural policies more on participation in cultural production and artistic performance.

Find out more information at www.nordiskahandikappolitiskaradet.org

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Discriminatory inaccessibility

The Ving Travel Agency entices people to travel all over the world, yet wheelchair users cannot even get into Ving's shop in central Oslo. This was the first case to be tried according to Norway's new law that classifies inaccessibility as discrimination. That was a year ago, but the shop still looks the same. Society will not change overnight, as the Norwegian Equality and Anti-Discrimination Ombud (LDO) confirms.

The Norwegian Anti-Discrimination and Accessibility Act came into force on 1 January 2009. The Act means, among other things, that premises that are open to the general public must be universally designed. A disabled person must not be directed to some form of special solution.

The Act had only been in existence for seven days when the first report came in to the Equality and Anti-Discrimination Ombud. The

Norwegian Association of the Disabled (NHF) reported that wheelchair users were being discriminated against because there is a difference of 14 cm between street level and that of the door to Ving's shop at Karl Johans gate 18 in Oslo.

Ving argued that they are not discriminating against wheelchair users as there is another shop 500 metres away which everyone can get into. The Equality and Anti-



The Ving office in central Oslo was the first case tried according to the new law.

Photo: Norwegian Association of the Disabled.

Elisabet Lier Haugseth, departmental manager at the Equality and Anti-Discrimination Ombud, believes the law has an effect, but that it takes time.

Photo: Bente Bjercke

Discrimination Ombud (LDO) supported the line taken by the Association of the Disabled. To the LDO, directing people to another shop is an unacceptable special solution. In that case, disabled customers could only go to a specific shop, while other customers may choose freely.

Ving accepted the decision by the LDO, yet despite that wheelchair users still cannot get into the shop.

Christian Grønli, Ving's sales manager in Norway, explains that there are a lot of people involved who will need to come to an agreement in order to find a good solution.

"We are working with the property owner, the Directorate for Cultural Heritage and the Cultural Heritage Management Office. This is about making changes to the frontage, and we are not allowed to build in such a way that it creates an obstacle on the road."

Elisabeth Lier Haugseth, manager of the legal unit at LDO, believes that Ving are doing what they can to solve the problem.

"Norway will not become accessible overnight just because we

have a new law. It often takes time before the reports result in practical changes. This requires cooperation. Nor is it the people who own the buildings who are reported; it is those who have the business."

Effects are a long time in coming

Arne Lein, chairman of the Norwegian Association of the Disabled, had not been counting on changes overnight, but he did think that things would move more quickly.

"I do think it's been going on for a long time. I had hoped for a greater effect."

Elisabeth Lier Haugseth at LDO believes that accessibility will improve greatly in a few years once the effects of the new Norwegian Planning and Building Act are felt. This comes into force in July this year. The new law will stipulate requirements for universal design right from the start.

"It will lead to pressure to build in an accessible way. Then, it will be much more effective to do that than to come back later and make adjustments," says Elisabeth Lier

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The law also requires information via the Internet that is meant for the general public to be accessible. There are also requirements for workplaces, schools and training institutions to be adapted as well as activities for children and the services provided by the local authority.

The official name of the Act is LOV 2008-06-20 nr 42: "Lov om forbud mot diskriminering på grunn av nedsatt funksjonsevne (diskriminerings- og tilgjengelighetsloven)" (Act for the prohibition of discrimination on the grounds of disability (Anti-Discrimination and Accessibility Act)).



Haugseth.

When it comes to putting measures in place, inaccessibility is not just a matter of time. It is also about money. The Anti-Discrimination and Accessibility Act states that no requirements may be set which place a disproportionate burden on the company.

Too expensive

In Ving's case, this was not a problem. The company has not said anything about the cost of the measures. A number of others who have been reported have indicated that it will be too expensive.

"Some of them have been very quick to say they cannot afford any measures," says Elisabet Lier Haugseth.

Cases are decided on a one by one basis on the part of the LDO. An important factor is what the

rental contract is like.

"We had one premises where you needed a lot of staircases to get in. As the contract was about to expire, we did not impose any requirements. On the other hand, I don't believe we would have accepted the premises if they had renewed the contract," says Elisabet Lier Haugseth.

The statement by the LDO is not legally binding, but if it is ignored the case may be passed to the Norwegian Equality Tribunal. If the Tribunal concurs with the LDO, this could lead to heavy fines. This has not yet happened.

"In one case, a music and games shop, we have not received any reaction. That case is currently with the Tribunal," says Elisabet Lier Haugseth.

In general, she feels there is acceptance of the law. Arne Lein, of the Norwegian Association of the Disabled, also believes the law has been received positively.

"What is most pleasing is that many people are now correcting faults even though they have not been reported. We are also starting to notice a different attitude in the building industry. That is very positive," says Arne Lein.

Not systematic

Is there any advice that could be given to other countries who are considering introducing corresponding laws? Elisabeth Lier Haugseth points out the importance of providing lots of information before the law is introduced. She herself has given some thought to what is needed if the system is to be perceived as being just.

"We base it on the reports that come in, and after all it is not at all certain that those who are reported are the ones who have committed the most serious faults. Another solution might be to have an inspection authority to provide more systematic surveillance," says Elisabeth Lier Haugseth.

Facts

The sectoral network of the Nordic Council on Disability Policy for building issues and community planning is working on a "Town for All" project. Inspirational conferences are being arranged in the Nordic region for politicians, community planners, architects, etc., and the "design for all" thinking is being communicated in various ways to the local authorities. Design for All (Norway: Universal Design) is part of the Council's overall strategy for a society that is accessible to all its citizens. It is aimed to make "Design for all" a prerequisite of all community planning.

A universally designed Norway by 2025

The new Anti-Discrimination and Accessibility Act is part of a bigger goal: a universally designed Norway by 2025.

It is an ambitious plan, but one that is possible to fulfil. This is according to the five Norwegian ministers who will be responsible for the action plan that will lead to the goal.

Priority is being given to four areas: IT, planning of cities, towns and areas outside the home, buildings and transport. More or less everyone should be able to use IT, travel on public transport and live and spend time wherever they wish, even though they may be disabled, without having to make use of special solutions. The politicians believe that accessibility is good not just for disabled people but also for families with children and the elderly, who can also have difficulties in getting by in certain environments.

Easier to get work

An accessible society is seen as a foundation for the creation of a society of equal opportunities for all. Not least, the politicians are hoping that this will lead to more disabled people receiving training and employment. This is good for the individuals and for society as a whole.

In order that the goal can be fulfilled, the issue has been given a high priority. All departments have a responsibility in this area. In other words, in people's normal activities they will need to take into account the conditions for disabled people.

"The state secretaries in the departments will retain responsibility for the sector and for coordination. The fact that this is being

taken charge of at such a high level shows the importance of these issues," says Inge Ovesen, departmental manager at the Norwegian Ministry of Children, Equality and Social Inclusion.

There are also high demands on cooperation. This applies at local, regional and national level as well as between departments. Politicians and civil servants at all levels must also have detailed talks with representatives of disabled people.

"The policy interest organisations receive NOK 150 million per year for their work. That is a large sum and shows how important their critical voice and participation are," says Inge Ovesen.

Requirements in the new laws

Laws and regulations need to function as a constant reminder that all development of activities addressed to the general public must employ universal design. This principle must be included right from the planning stage. As well as the new Planning and Building Act and the Anti-Discrimination and Accessibility Act, there have been a range of laws that have emphasised accessibility. These include the Norwegian Public Procurement Act, the Norwegian Education Sector Act and the Norwegian Universities and University Colleges Act.

To monitor whether the plans are really being adhered to, indicators are being developed for universal design in central areas. Indicators are measured on the basis of how the plan is proceed-

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Inge Ovesen, Head of Department at the Norwegian Ministry of Children, Equality and Social Inclusion



Arne Lein, Chairman of the Norwegian Association of the Disabled (Photo: Werner Juvik)

ing. For example, what is the rail transport like? Can everyone manage to use the trains without any problems? Choosing which indicators there should be is an important part of the job.

“From the disability movement, they might have wanted very detailed indicators. It is a question of agreeing on just the right level.”

Deltasenteret, a government skills centre, has been tasked with documenting and monitoring how things are proceeding with the indicators. This will allow the politicians to see whether the work is proceeding according to the action plan.

Not enough money

There is a long way to go until 2025, but there are already those who doubt that the grand goals are really achievable. Arne Lein, chairman of the Norwegian Association of the Disabled, does not believe it is possible.

“The local authorities have not been given enough money to turn this into reality,” says Arne Lein.

The fundamental principle of the business plan is that money should not be earmarked for the realisation of universal design. It should

be covered within the normal budget. However, the principle is not an absolute one. In certain cases, the politicians have realised that additional money will be required. The biggest investment is in the transport sector, where NOK 4.47 billion has been set aside for 2010-2019. Lesser sums have been set aside in many areas – for example, NOK 25 million for the office of the Directorate for Cultural Heritage and NOK 75 million for the building of environmentally friendly and accessible student flats.

Hopeful about the future

Inge Ovesen believes that additional money is needed from time to time, but that overuse creates a dilemma.

“The starting point is that increasing skills will mean that we need less and less earmarked money. For example, the local authorities can now obtain favourable loans for building schools. So, in the case of those investments, working on universal design just becomes a natural part of it,” says Inge Ovesen.

Ovesen points out that some towns have achieved great success with accessibility without additional money.

“The better you become at starting from a position of universal design, the less the need for special money. One city well known for its success with accessibility is Barcelona, where no special money has been set aside. Here in Norway, Kristiansand has been the most successful. They, too, have not received any additional money.”

Is it reasonable, then, to believe that the whole of Norway will develop in the same direction as Kristiansand? That the whole country will be universally designed in 15 years’ time? Inge Ovesen is hopeful.

“Of course, I can’t guarantee we will succeed, but I have great confidence that we will because we are working in such a systematic way,” says Inge Ovesen.

UN convention

In article 9 of the UN convention on the rights of persons with disabilities (Accessibility), a requirement is placed on countries to implement measures that will remove obstacles and barriers to accessibility, including with regard to buildings, roads, methods of transport, schools, housing, healthcare facilities and workplaces.

Deltasenteret

Deltasenteret is the state's skills centre for participation and accessibility. The central element is universal design. This means designing products and the surroundings so they can be used by everyone. Deltasenteret provides advice and guidelines, performs developmental work and works alongside specialists within the field on projects and networks. On 1 June 2010, Deltasenteret moved from the Norwegian Directorate of Health to the Norwegian Directorate for Children, Youth and Family Affairs. Deltasenteret is a department, yet at the same time has its own management committee consisting of representatives from specialised environments, local authorities, county councils and interest organisations for the disabled persons. The centre employs nine staff of varying professional background.

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Indicators in Norway

The progression in developmental work on indicators of universal design varies in the different sectoral environments. Deltasenteret's status report from the professional bodies and registration authorities is linked to the development work and will be responsible for the development of their contributions and products in the various areas.

In the field of transport, three national indicators have been developed in each of the areas – road, railway and air travel. These have been published in the National Transport Plan for 2010-2019, and work is now in progress on the foundation of these.

National indicators for buildings have not yet been defined, but are expected during March 2011. A new Norwegian standard for building and housing is ready and work is now being done on a Norwegian standard for outdoor areas.

In the field of ICT, the plan is first and foremost for indicators in the fields of the Web, learning platforms and vending machines. In 2010, new regulations are being commissioned regarding accessibility to the Web. It is planned to start measurement of Web accessibility in 2012.

Nordic indicators

The sectoral network of the Nordic Council on Disability Policy for transport issues has produced an initial proposal for indicators of Nordic interest, i.e. measurement tools to enable the monitoring of developments in the issue of accessible public transport at various times. The Council has approved a declaration regarding public transport that has been sent to the Nordic Council of Ministers. It includes a proposal for the continued development of work on indicators and the production of joint Nordic guidelines on how to make public transport accessible. The Council's transport network is following up the matter in a letter that will be delivered to the Nordic transport ministers, where it is emphasised among other things that universal design or design for all must be a prerequisite of all orders, purchases and contracts, whether the player in question is a public authority or a private company.

Easy to get support on difficult issues

Wherever you live, access to specialised knowledge should be the same. This is one of the foundations of VISO, the National Knowledge and Special Counselling Organisation in Denmark, where anyone can go for advice on complex issues.



Jens Kofoed Mogensen, responsible in knowledge terms for VISO for adults, and Helle Thiele, Vice Director at the Danish Service Agency, are working on the quality assurance of advice from VISO.

VISO's office is in Odense. It is a fairly new enterprise. Helle Thiele, Vice Director at the Danish Service Agency (Servicestyrelsen), still has the beginning fresh in her memory.

"In December 2006, we started completely from scratch. We were standing here with empty premises, no staff and no telephones, and were about to embark on some-

thing completely new and put together staff from different cultures," says Helle Thiele.

Now, the operation is in full swing. Only the "Thrige" plate on the wall acts as a reminder that these premises belonged to a company that made pumps. Now, some 20 consultants work here. They take calls from experts and private

individuals throughout Denmark who need advice on difficult issues as far as the following are concerned:

- Children and young people with disabilities, including rare disabilities
- Children and young people with social or behavioural problems
- Vulnerable groups
- Adults with disabilities
- Social psychiatry
- Special training and specialised educational support to children, young people and adults

“These are areas where the experts until now have not worked together. It means we can now offer advice from a wide perspective. For example, we may be talking about men with a physical disability who take drugs,” says Jens Kofoed Mogensen, who is responsible in knowledge terms for VISO for adults.

Of course, the 20 consultants at the office in Odense cannot answer everything. Their task is often to pass the call onto one of the 140 experts in the country.

“The experts are people who are practically active within their fields,” says Helle Thiele.

The best experts

Before VISO came into being, experts were scattered throughout Denmark via local authorities and the administrative districts that were the regional authorities. Before 2007, they had official responsibility in the social area and the area of special education. Since 2007, there have no longer been any administrative districts, and the local authorities have full responsibility. VISO has come into being to support the local authorities. When VISO was being set up, the Danish Social Ministry asked the Association of County Authorities, Local Government Denmark and the user organisations to point

out the most reliable experts.

A thousand suggestions were received, and from these 140 experts were chosen.

“We are now working to quality assure the operation.

Anyone who contacts VISO is facing an unusual and difficult problem which they need advice to solve.

“For example, it may be a family that has a child with a developmental disorder who finds it difficult to interact with his or her siblings. This may result in an expert from VISO having a number of talks with the parents, but that is the end of it. This is not treatment, but rather advice as to how to take things further and where to go next. The best thing is if we are also able to set up a dialogue with the local authority,” says Helle Thiele.

A call from a social worker in a local authority may be about an acting-out person with dementia they cannot cope with.

“Perhaps the staff have tried everything without getting anywhere. In that case, an expert from VISO can provide advice,” says Helle Thiele.

Does not take decisions

VISO can also support the local authorities in complicated investigations, but it is important that they are never anything but advisors. The experts at VISO are not the ones who make the decisions. This is something the local authorities must do. Nor may a dissatisfied user turn to VISO as a means to having a local authority decision changed.

There have been some discussions as to the extent to which VISO is used and how usage can increase. There has been a fear that a number of local authorities would not wish to call as they are concerned that VISO might come up with advice that was costly.

“I think there was that anxiety at the start, but that is no longer the case. Our experts provide advice based on the financial context in Denmark,” says Helle Thiele.

“Then, too, a piece of advice that seems expensive in the short run can be cheap in the long run. For example, if the advice is to train staff about dementia, it may be expensive at first but it will then lead to fewer people being needed to care for a person.”

VISO not only gives advice in individual cases but is also able to help with more general problems, and, even when the issue is about specific advice, similar cases often arise and then you know how to manage the case.

“In an appraisal of VISO, it emerged that in one in three cases the social workers have also been able to use the advice in other cases. That feels good. That is when we notice we are making a difference,” says Jens David Kofoed Mogensen.

Many questions about ADHD

The questions that come in to VISO also provide a hint as to the areas where more support and research is required.

“We get a lot of questions about ADHD. We have taken this and made it clear to the Ministry of Social Affairs, which has decided to invest DKK 25 million in a survey,” says Helle Thiele.

Besides proving advice, VISO’s task is to gather and cultivate

knowledge and ensure that it is disseminated. There are 14 resource centres in VISO, and they are responsible for knowledge development within their own areas. For example, there are resource centres for social psychiatry, visual disability, hearing disability, rare diseases and disabilities and autism.

“Our resource centres have an overview and are also able to come up with suggestions for research needed within their areas. One example is that there is a need for scientific studies into children who start to hear using cochlear implants (CIs). There is little knowledge as to how this affects the children. “This is the sort of thing we might draw attention to,” says Helle Thiele.

Helle Thiele and Jens David Kofoed Mogensen are not aware of any similar organisation in any other country, at least not one offering such a broad spectrum of advice. One of the things that surprised Helle Thiele most was the great need to inform people about VISO.

“It is not enough for us to tell the local authorities once about our existence. We need to do it time and time again,” she says.

“The explanation, of course, is that they so rarely contact us. This means that they are not always thinking about the fact that we are there, especially if new staff arrive and old staff leave,” says Jens Kofoed Mogensen.



The 14 resource centres are:

- Danish Centre for Rare Diseases and Disabilities
- Danish Dyslexia Resource Centre
- The Stuttering Information Centre of Denmark
- Danish Centre for Assistive Technology
- Danish National Centre for Autism
- Danish Disability Resource Centre
- Danish Information Centre for Acquired Deafblindness
- Danish Resource Centre on Congenital Deafblindness
- Danish Epilepsy Resource Centre
- Danish Brain Injury Resource Centre
- Danish Hearing Disability Resource Centre
- Danish Psychosocial Rehabilitation Information Centre
- Danish Visual Disability Resource Centre
- VIKOM – Danish Resource Centre on Communication and Multiple Disabilities concerning Children and Young People without Spoken Language

The resource centres have particular knowledge of:

- functional capacity
- processes
- enterprises
- methods
- requirements for provisions
- applied knowledge
- roles
- collaboration
Collaboration between user and professional,
mutual collaboration between professionals, etc.
- complexity
- knowledge bearers
- communication

VISO

VISO is a unit within the Danish Service Agency. The Danish Service Agency is part of the Danish Social Ministry. Its task is to make an active contribution to knowledge-based social policy that will lead to effective social services for the benefit of citizens. VISO is part of the Danish Social Ministry but with its own specialised management board that includes representatives of disability organisations and Local Government Denmark, which is a member and interest organisation for Denmark's local authorities.

A door opened

One day in 2007 Ása Björk Gísladóttir was sitting and leafing through the pages of Iceland's biggest newspaper Morgunblaðið. All of a sudden she noticed an advert that totally grabbed her attention.

The advert described a Diploma Programme at the University of Iceland for people with intellectual disabilities. This was news to Ása Björk - and for everyone else in Iceland - as there had not previously been courses on offer at a university level for this group of people. Suddenly, a door had opened to a world of exciting opportunities.



The now 30 year old Ása Björk did not need much time to think things over. She had previously attended school at Öskjuhlíðarskóli, which is Iceland's only special school for pupils with intellectual disabilities. Following this she studied at Borgarholtsskóli, a further education school offering varied course

opportunities, including a programme for students with learning difficulties.

"I was well-received by both the teachers and the students at the University of Iceland. The reception was not as good from all of the teachers, but it turned out that what was needed was a little time

to get used to things. I still have many friends among my former fellow students."

The course itself was organised with a preliminary semester where there were only diploma students. During the remaining three semesters they worked together with the students from the social-worker programme. In the fourth and final semester they choose a subject, where 1-2 students from the Diploma Programme participated in each group and worked together with students from the social-worker programme.

"The social life and the period of practical training suited me best. The most important thing I took from it all was the awareness of the extent to which I can take care of myself. I can definitely recommend that all others in the same situation begin this or a similar study programme. You just have to jump in at the deep end!" Today Ása Björk works in a part-time job in a kindergarten, but her dream for the future is a job as an assistant at a further education school. However, she does not think that the time is right to take the plunge at the moment, mainly due to the prevailing situation in society.

The second clutch of students are already well underway. Like the first class they are no doubt happy that a door, which had been shut for a long time, was opened when the University of Iceland choose to offer this Diploma Programme.

New times at the old university

The University of Iceland was founded in 1911.

Nearly one hundred years later access has been given to a new group: students with intellectual disabilities.

"It has gone fantastically well," says Guðrún V Stefánsdóttir, initiator and university teacher.

In June 2009 the time had come to issue diplomas to 22 students who had spent two years studying at the Faculty of Social Work. One can wonder whether there have ever been prouder students. A pride that they could share with teachers, parents and others who had actively participated so that people with learning difficulties could also have the opportunity of a university education. There has been a great deal of pressure on the authorities to provide the opportunity of further education for people with intellectual disabilities.

The university scheme is not yet permanent, but the trial project continues. In October 2009 20 new expectant and, perhaps, slightly nervous students began.

Guðrún V Stefánsdóttir, initiator and teacher at the University of Iceland, was a little nervous at the start of the project, wondering how things would turn out.

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“Not for the students in question. But I was a little nervous about how they would be received by the teachers and the other students. At the start the programme was associated with the Pedagogical University of Iceland, but it is now associated with the University of Iceland, which is a more traditional and prestigious environment.”

At the beginning Guðrún V Stefánsdóttir's forebodings were partly confirmed.

“Some of the teachers and students had certain expectations - in some cases you could describe them as prejudices. They feared that this project would lead to a deterioration of the university; but the teachers have more or less come round now.”

Guðrún V Stefánsdóttir and her colleagues have carried out an evaluation which shows that the teachers are very positive. The new group of students has led to the teachers learning more about different needs in relation to teaching and how it is possible to work in an inclusive manner. Many teachers think that the programme has improved and that it has provided better knowledge about all of the students.

“This leaves the discussion about who the university is for. There are other groups who also do not have access to the university today, for example because they have not met the admission requirements.”

Guðrún V Stefánsdóttir believes that the discussion about the university can now be compared to the manner in which people once discussed who should study at upper secondary school. Now there are upper secondary school programmes for all types of students.

The diploma students with intellectual disabilities have studied together with students following the programmes in social work, the programme for pre-school teaching and the teaching programme. They

have taken all of the subjects together but have had different types of practical training.

“A couple of the other students have acted as mentors. They have helped to explain the contents of the lessons. In some cases the lectures have also been in a simplified language, though a number of the courses have not been altered.”

Being a mentor is completely voluntary.

“Many of the mentors will of course come to work with people with intellectual disabilities. So the mentor scheme can be seen as being part of their education.”

The need for support varies

Guðrún V Stefánsdóttir estimates that 4–5 of the diploma students would have been able to take the examination in the same way as the other students with the proper support. But most require more help than that.

“A number of them cannot read and write,” says Guðrún V Stefánsdóttir.

Regardless of background the assessment shows that the students have greatly benefited from the programme. They have learnt new things and are able to handle more work tasks. Many of them have also found work after the programme. For example as assistants at pre-schools or schools and in connection with after school activities for children with disabilities.

“Six of them have found work. That is a lot in view of Iceland's economic situation. The programme has made it easier for them to find a job.”

But going to university is not just about getting an education. Perhaps having a sense of belonging is just as important; being one of the students.

“At the beginning many people were nervous. Supporting them at the university has been the task of the mentors. On the whole things

have gone well. Many have made friends from among the other students. And they have also gained in self-confidence.”

“The assessments lead us to ascertain that it is often the case that students with learning difficulties are not adequately challenged, which means we must ask ourselves about the opportunities and requirements that the school system is able to offer.”

Guðrún V Stefánsdóttir hopes that the trial project will be made a permanent part of the university and she believes in inclusive learning in general. That is not to say that there have not been difficulties at the university. Two of the students felt they were treated like children by the teachers at the university. Many parents have felt the information provided by the university was inadequate. There have also been complaints from the parents. Many have felt that the demands made were too great; others that they were not great enough. Many parents believe that special needs education is the right way to go.

“We are still at the experimental stage. We are continuously trying to improve the programme. We have now increased the support provided for the students and we have developed the mentor scheme.”

There has been a great deal of interest in the programme. Guðrún V Stefánsdóttir and her colleagues have received many inquiries from other countries that are considering the introduction of the same system.

“The most important factor for being successful is a positive attitude. You have to believe that everything is going to go well.”

Contact

Guðrún V Stefánsdóttir
The University of Iceland:
Tel: +354 525 5366
e-mail: gvs@hi.is

The UN Convention

Article 24 of the UN Convention on the Rights of Persons with Disabilities requires that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. Appropriate measures shall be taken to ensure this.

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real life



FINANCE CRISIS ON THE VULCANO ISLAND



Volcanic eruption in the Eyjafjallajökull-area (3 April 2010)

The Welfare Watch

Iceland has experienced a great deal of turbulence - both economically and in its nature. It is not possible to manage a volcano, but by using untraditional methods it is possible to ensure continued good service for persons with disabilities, according to Icelandic politicians and officials.

Red-hot lava, poisonous steam, smoke and ash poured out of the volcano on Fimmvörðuháls in the Eyjafjallajökull area. The eruption, which began on 20 March and ended on 12 April, was however relatively small by Icelandic standards, so that the nearby agricultural areas were not threatened to any great extent. The tourist eruption, which is how Iceland likes to describe volcano eruptions of this size, rather conveniently took place just before the tourist season, which meant more tourists than usual at Easter. A new and much larger eruption then began during the night of 13 April in Eyjafjallajökull itself, at the top of the glacier. The ash cloud from this eruption ruined the beneficial tourist effect and impacted on air traffic over large parts of Europe. Material damage was suddenly no longer a private matter for the Icelandic people.

The financial crisis, which began in the autumn of 2008, hit Iceland just as suddenly and unexpectedly

as the volcanic eruptions. There had been small indications prior to it, with overheating in the economy and subsequent tremors around the island like those beneath Eyjafjallajökull prior to the eruptions. However, the crisis hit much harder than the fire from the Earth's core.

On the surface society looks just as idyllic as the white glaciers on top of Eyjafjallajökull before the eruptions - but looks deceive. Newly built castles of glass stand shoulder-to-shoulder in the townscape, while large, modern residential areas look inviting from a distance, but rather deserted on closer inspection. Large, expensive cars can be seen everywhere, but most of them remain parked most of the time; they are either leased cars which people can no longer afford to drive, or they are cars purchased with borrowed money. Bankruptcies, cutbacks and redundancies are words often used in the media.

The Welfare Watch

Drastic events sometimes demand drastic actions. The Minister of Social Affairs and Social Security therefore appointed a steering committee on 16 February as a welfare watch, with the aim of closely monitoring the social and economic consequences of the banking crisis for families and individual citizens of the country. The steering committee's role was to operate the welfare watch, present proposed solutions and coordinate the gathering of information. The steering committee works closely with other institutions and NGOs who themselves work with families and individuals, and it regularly holds meetings with these parties.

The steering committee aims to gather information about measures that have already been initiated to offset the effects of the economic crisis and to chart all governmental, municipal and private contingency plans. Furthermore the welfare watch will study the most vulnerable groups of people and present suggestions that are as far as possible directed towards these groups.

Governmental demands for savings

The Icelandic government has presented actual demands for savings in a number of areas, including the regional offices under the Ministry of Social Affairs and Social Security. Widespread savings can hurt; when it came to disability matters the decision was therefore taken to work in close consultation with the people who use the services provided, their relatives and the field of practice. Disability pressure groups and relevant unions were also kept updated, but were not directly involved in the work.

Various scenarios were presented to the regional offices, in which they were to decide how it would impact

on their activities if a reduction of 3, 5, 7 or 10 percent were carried out. The regional offices were to assess the impact on the various areas of service; i.e. children's services, adult (18 and above) support, housing, rehabilitation etc. The offices were asked to assess the impact on the users of the service made by the various proposals for savings on a scale from minus 5 to plus 5.

"The assessment was to include how the change will affect economy, users and employees. We have worked with the aid of the consensus method and looked at the solutions we could reach in unison."

Eventually the politicians decided that the area of disability did not need to make such large savings as first proposed.

"Instead of a 10% saving things ended with a saving of 2.6 percent. Which was not so dramatic," says Þór Þórarinnsson.

The work that was carried out in the working groups will not be simply discarded, Þór Þórarinnsson feels.

"We have received many good ideas about how service can be delivered more efficiently. We are now reviewing disability services so that we can meet the challenges of the coming years in the best possible manner. The suggestions received are very beneficial in connection with this."

After the interview with Þór took place events have developed very quickly in Iceland and it has turned out that the situation is so bad that cutbacks of between 5 and 10 percent within the welfare area will have to be made over the next two to three years, which is very dramatic.

Regardless of the volcanic eruption, continuous efforts are being made to find savings within the government's various areas, while attempts are made to maintain a certain level of welfare and to spare society's most vulnerable groups.



*Þór Þórarinnsson,
Head of
Department at
the Ministry of
Social Affairs and
Social Security of
Iceland.*

Interpreters for people with speech impairment

"We are the only country in the world with this entitlement," notes Ilona Toljamo of Finland's CP Association.



Marianne Kiili uses her eyes to point to Bliss symbols so as to explain to Jykä Pietinen about her new communication material. Nina Ait Brahim interprets.

Marianne Kiili has CP and a severe speech impairment, and communicates via the Bliss symbol system. Satu Rautiainen has CP impairment such that those who do not know her well may have difficulty understanding what she is saying. Olli, a teenager, is autistic and needs support to communicate.

Marianne, Satu and Olli are three of about 500 people in Finland with speech impairments who have the right to an interpreter. Finland is the only country in the world where people such as Olli, Marianne and Satu have such a right.

"It is possible that there are interpreters in other countries but it is not an entitlement anywhere else," explains Ilona Toljamo of Finland's CP Association.

It was the CP Association and five other disability organisations

that pushed to bring this about.

"We worked together with organisations for the deaf and hearing-impaired. At first they did not think that people should have an interpreter if they did not speak a different language, but they gradually understood the need. It is a really important service. It is the only way to guarantee that people with speech impairment are treated the same as everybody else," says Ilona Toljamo.

The legislation came into force in 1994. Prior to that people with speech impairment had to ask friends, relatives or personal assistants to help them. In most situations this continues to be the case. Interpreting is primarily meant to be for situations where it is particularly important for there not to be any misunderstandings, for example in discussions with public authorities.

"If it is your relatives who are to do the interpreting it is not you who has control. And being a personal assistant is not the same as being an interpreter. An interpreter is a person who has been trained to do the job, who has learned to be neutral and who has the skills required to manage any ethical issues that might ensue in connection with interpreting."

The interpreter's job varies depending on who it is being done for. Satu's speech is indistinct so the interpreter's job is to understand Satu and explain to others what she is saying. As a researcher, Satu uses an interpreter in situations where it is particularly important that she is not misunderstood, such as when she gives lectures.

Using the eyes to point

Marianne Kiili needs an interpreter when she communicates with people who do not understand the Bliss symbol system. She uses her eyes to show which symbol she wants to use and the interpreter explains what Marianne wishes to say. She also needs an interpreter to read and write emails. It would not be possible for her without an interpreter.

Olli is 14 years old and is autistic; he needs various types of support. The interpreter has to convey Olli's indistinct speech and support him in the use of an Imagetalk Symbol Writer so that Olli can get other messages across by clicking on symbols. The interpreter should also draw others' attention to how Olli communicates.

One of the interpreter's jobs is to help and support the speech-impaired person to communicate. This involves the interpreter being able to update communication aids such as symbol maps, speech equipment and computer-based programs as agreed with the speech therapist. In Olli's case the interpreter has to update his Imagetalk Symbol Writer.

"In Finland we are really quick to adopt the latest methods for how

people with speech impairment can communicate. This has been influenced by the right to have an interpreter," says Ilona Toljamo.

The maximum amount of interpreter time it is possible to have is 180 hours. Most people use only around 80 hours, but there are also people with a much greater need. If a person requires it for work or studying, it is possible for them to get extended interpreter time.

"The interpreter makes it possible for these people to have a voice. It is fantastic. It means that it also becomes clear how much they have to say," says Ilona Toljamo.

The use of interpreters is on the increase

Young people use interpreters to a greater extent than older people. Ilona Toljamo believes that the use of interpreters is going to increase. It used to be difficult to get hold of trained interpreters but the situation has improved enormously. Since 2001 a 40-week training course has been in place and there is training for Swedish-speaking interpreters as well.

Up till now local authorities have been responsible for the procurement of interpreters, but from 2010 the system will be managed centrally by the Health Insurance Institution.

"We are absolutely delighted with this change. In some local authorities it has worked, in others it has not worked at all. Now it is going to be more uniform," says Ilona Toljamo.

The UN convention

The UN Convention on the Rights of Persons with Disabilities. Article 19 Living independently and being included in the community makes the point among other things that the state must facilitate the rights of persons with disabilities to full inclusion and participation in the community, including by means of personal support as necessary to prevent their isolation and detachment from the community.

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Satu and Olli appear on www.papunet.net where Förbundet för utvecklingsstörning (the Association for the Care of People with Intellectual Disability) provides information about communication disability and ways to overcome it.

Anyone wishing for more information can contact Ilona Toljamo, Finland's CP Association. ilona.toljamo@cp-liitto.fi
Tel: +358 9 5407 5480

Jerry – the first step towards modern recruitment

"It is going to become as self-evident for modern companies to recruit disabled people as for them to be ecologically aware." That is what Kenneth Bengtsson, the new chairman of the employers' association Confederation of Swedish Enterprise and President and Chief Executive of large enterprise ICA, had to say.



*The advertising clip with Jerry the trainee makes fun of the prejudices that people with Down's Syndrome can meet.
Photo: Carl Sundberg*

There is probably not a single Swedish person who does not know what ICA is. The company is one of the dominant chains of food stores. In recent years the company has also established a reputation for its soap opera format TV advertising. The public gets to know the characters in a store. The advertising reached a new level when viewers made the acquaint-

ance of Jerry, a trainee played by Mats who has Down's Syndrome. The advertisement makes fun of how the staff treat Jerry. How Ulf, Jerry's workmate, explains everything in an exaggerated way, while Jerry just wonders whether he is feeling all right. Kenneth Bengtsson was a little concerned as to how this would go down with the TV viewing public, but it exceeded

all expectations. Jerry has a Facebook page with 200,000 fans.

In connection with Jerry getting a trainee position in the advertising clip, the company also started its 'We can do more' initiative. The goal is for 500 – 1000 disabled people to be employed within the company. Recruitment is done in co-operation with other organisations including Samhall, a state-owned company that has as its goal to arrange for disabled people to get work. Kenneth Bengtsson thinks that Samhall's support is helpful. He hopes that in the future local authorities can also make it easy for companies that want to employ disabled people.

"I think these are issues that have to be managed and embedded at a local level – so one way forward would be to encourage every local authority to develop clear plans of action to give support to both private and public employers that want to take on disabled people. I also believe in tighter rules and regulations concerning all the physical obstacles preventing many disabled people from working in many workplaces.

Appreciated by employers

Kenneth Bengtsson expects more companies to follow ICA's initiative.

"Having seen how much this project has been appreciated – both by employers who have new employees and by those who have got new jobs with us – I am absolutely convinced that this type of issue is going to get an ever stronger foothold in many modern companies in the future."

But it cannot just be done to create goodwill for the company.

"I think it is important to feel a natural engagement with certain issues so as to be involved in the development of the areas that surround them – whether it is a matter of personnel involvement,

customer offers or more store-related issues. As regards involvement in the business sense it is also a matter of daring to stick your neck out and taking an initiative."

Efforts continue at ICA for more of those who are unemployed today to be able to show that they can do more.

"I hope that in the long run we can develop the 'We can do more' project to be the starting shot for something bigger. Our ambition just now is to take 'We can do more' to the next level which consists of our offices and warehouses around Sweden, not just the stores; we are in the process of working on procedures and routines to govern how to set about it in practice."

Samhall

Samhall is a company that is owned by the Swedish state. The purpose of the company is for people with disability to be developed through work. The company produces goods and services for which there is demand in a competitive market. It is required to operate profitably, but Samhall does not distribute a dividend. The money remains in the company. Samhall provides work and development for about 21,000 employees with disability each year. About 1,000 move on to jobs with other employers. Samhall offers employment services. People with disability receive individual work training and suitable forms of employment that increase their chances of getting work. Samhall is commissioned to do this by the Arbetsförmedlingen (employment office), Försäkringskassan (social security office), local authorities and employers.

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Kenneth Bengtsson, President and Chief Executive of ICA and chairman of the employer organisation Confederation of Swedish Enterprise.

A job coach means that more can get work

Working life researcher Øystein Spjelkavik would like to see many more job coaches, people who are in the workplace and provide support.

"This idea has proved to give excellent results, even for people with serious mental illnesses."



Øystein Spjelkavik hopes that coaches will become as natural a type of support at work as other aids.

It has become incredibly popular to engage a coach. People turn to coaches to get help with training, personal relationships, lifestyle, careers, etc. There is not much glamour around the coaches that Øystein Spjelkavik from the Arbeidsforskningsinstituttet (Work Research Institute) would like to see more of, but with their help those people who have the most difficulty getting work increase their chances considerably.

"The idea is to help people who

in various different ways have problems adjusting to a workplace. The issue may be social problems: school drop outs, drug addicts, people who have served time in prison, and so on. There may also be people who have difficulty adjusting because of serious mental illness."

There are several studies that show that job coaches work. Øystein Spjelkavik's own research is in this very area, but the study he thinks is the most persuasive comes from the USA.

"An American compilation of several studies shows that people with serious mental illness, such as schizophrenia, can have and keep a job if they have the support of a coach. If there can be successes with this group, which has such difficulty getting work, it is proof in itself that there are definitely possibilities for other groups as well."

Satisfied employers

The coach's job varies from person to person. In some cases it can involve the coach being present in the workplace all the time. In others the coach may only have occasional telephone contact. As well as supporting the employee, the coach is also there for the employer.

"I have interviewed many employers who would not have taken on these people if there had not been a coach involved. They would have thought that the risks were

just too great. When there is a coach there are no risks, nor any additional costs. The employers are pleased. They have access to labour.”

One condition for a successful outcome is that the coach should not disappear. Follow-up is a must.

“One project involving coaches had the researcher examining what had happened a year after the coaches had gone. It turned out that all the subjects in the study had lost their jobs.”

Job coaches are part of what is called supported employment. To date this exists only on a small scale in the Nordic countries.

“It needs to be developed further. Those people who have the most difficulty getting work cannot be supported in any other way. You don’t reach them with Danish “flexible jobs” or Swedish wage subsidy schemes or other financial support. It’s not enough.”

Øystein Spjelkavik does not believe that it would help just to work with employers’ attitudes either.

Attitudes cannot be changed

He takes as an example the IA agreement in Norway, an agreement on inclusive employment that is backed jointly by unions, employers and the state. One of the aims of the agreement is that people with a reduced capacity for work should get employment.

“It has not produced much of a result. There are some employers who are open to taking on people with a reduced capacity for work, but they have not increased in numbers as a result of the agreement. The practice has not spread.”

Øystein Spjelkavik’s view is that it is important for it to be more clear who actually has the most difficulty getting work.

“Which is the biggest group that is banging on the door of the NAV (Norwegian Labour and Welfare

Administration) seeking help to get work? It is not people with physical disabilities who constitute the biggest challenge.”

Øystein Spjelkavik believes that the time is ripe for psychosocial support to be seen in the same light as other types of aid.

“I have a problem with my back and have therefore got a special chair. Another person has a problem with social interaction; that person gets a coach. It’s not particularly remarkable. They are just different types of support.”

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Facts

The employment network of the Nordic Council on Disability Policy is involved in various projects and with Nordic conferences and seminars that emphasise good models to lower the thresholds in the job market for people with disabilities.

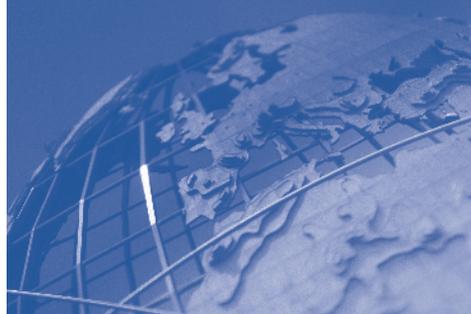
Among other things the Council’s employment and training networks work together to find good models for the transition between school/educational institution and working life.

Find out more information at www.nordiskahandikappolitiskaradet.org

The UN convention

The UN Convention on the Rights of Persons with Disabilities

Article 27 Work and Employment requires the recognition of the right of persons with disabilities to work, on an equal basis with others. This includes providing support so that they may be able to find, get and keep a job, and even be able to go back to employment.



Search for a better disability policy

Handisam, the agency for the co-ordination of disability policy, has done a situation analysis for the next five to ten years. This picks out the societal trends that imply the biggest challenge for disability policy.

"By selecting just nine trends we have set out a priority list. This is something that many will find useful," says Handisam's director-general Carl Älfvåg.



Carl Älfvåg, director-general of Handisam, feels there is so much to be done in terms of disability policy that it can become overwhelming, so analysis and discussion are necessary as to what should be prioritised.

Spanarna is a popular Swedish radio programme where famous personalities, half seriously and half in jest, try to work out what trends are characteristic of the times. Handisam has made use of "trend observers" as well, but with a dead-serious purpose. One Handisam working group put together a draft whereby they narrowed down the most important situational trends according to Michael Porter's model¹. A group of trend observers was then formed who were introduced to the situation analysis and

held their own meetings to discuss trends, instances of trends, consequences and challenges.

"A lot of contact was had with the disability movement in the course of this work," says Carl Älfvåg.

By the end of 2009 the study was finished and then the situation analysis started to be used. Carl Älfvåg explains that he last used it when he met the representative from HSO Skåne, which is a co-operative body for disability associations in Skåne.

"This is a really good basis for a

1. Gent L och Laurent Omvärldsanalys i praktiken (2008) (Gent L and Laurent Situation analysis in practice)

discussion as to what issues we should be working on,” says Carl Älfvåg.

The same applies to all those who work with disability policy in different government agencies.

“There is so much to work with that it is easy to become overwhelmed as to where to start,” says Carl Älfvåg.

He does not view the situation analysis as an absolute truth but rather as a starting point for a discussion about how priorities should be set.

“We use the analysis and it leads to discussions exactly as was intended. I know that people in the other Nordic countries would like to have something similar,” says Carl Älfvåg.

The nine trend areas that were picked out are: Increased international demand, increased competition for public resources, increased use of IT in everyday life, more and new digital arenas for meetings and communication, more older people, increased travel, a more flexible labour market, increased privatisation and increased streaming in schools.

The nine trend areas and some of the challenges are as follows:

Increased international demand

Ensure that accessibility and rights for disabled people are included in those directives that are proposed at EU level

Increased competition for public resources

Find creative and effective solutions to increase the participation of disabled people, first and foremost in working life

Increased use of IT in everyday life

Design technological solutions so that they work for everyone; standardisation is an important tool here

More and new digital arenas for meetings and communication

Design social media so that they work for everyone by way of, for example, standardisation

Facts

The sixth network of the Nordic Council on Disability Policy works with the UN Convention on the Rights of Persons with Disabilities and the Swedish Handisam model for situation analysis as a basis to establish priorities for disability policy. The network includes national ministries or government agencies that have co-ordinating responsibilities with regard to disability policy. Handisam’s director-general Carl Älfvåg belongs to the network.

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More older people

Take note particularly if older women have specific problems in terms of accessibility.

Increased travel

Establish good co-ordination between means of transport and the responsible authorities so that the whole journey works for disabled people

A more flexible labour market

Ensure that all parts of the educational and training establishment are clear that they must work towards getting disabled people to develop the right skills to get into the job market.

Increased privatisation

Create conditions, in the form of legislation, regulations, procurement and the like, so that the same demands are made on all participants regardless of type of operation

Increased streaming in schools

Work towards providing equivalent conditions for disabled students in schools so that they have the same opportunities in terms of secondary school, higher education studies and employment

Policy



The Disability Councils in Denmark – a success

A study carried out by the Ministry of Social Affairs that was published in 2009 showed that the disability councils have a great deal of influence on, and importance for, local policy. Rødovre is one of the municipalities where people are most satisfied. An important explanation is the high-level of influence of the disability organisations.

From 2006 all municipalities in Denmark have been legally required to have a disability council. The municipal council is obliged to listen to the disability council with regard to all initiatives within sectors that are of relevance for persons with disabilities and handicaps. The disability councils have the task of advising the municipal council on questions of disability policy and communicating points-of-view between citizens and the municipal council. The councils consist of an equal number of representatives from the disability organisations and the municipal council.

The municipality of Rødovre has had a disability council since 2003, when it was a voluntary organisation, and it is one of the municipalities with the best functioning cooperation between the disability council and the municipal council. The Nordic Centre for Welfare and Social Issues has spoken to two of the members of the disability council in an attempt to pinpoint why the cooperation functions so well in Rødovre.

Britt Jensen is chairman of the social and health committee. She has been a member of the municipal council for many years and was one of the initiators in connection with the establishment of the disability council in 2003. She has been a member of the council ever since, just like Torben Bjørn Andersen. He represents the disability organisa-

tions. He is elected by the Danish Muscular Dystrophy (MS) Fund.

The council holds meetings where they discuss and make decisions about current cases and problems. All the way back to when having a disability council was voluntary the position in Rødovre was that a council made up of administrators was not well-suited for controlling the work of the very same administrators; there is therefore an executive committee in the council and all of its members are members of Danish disability associations.

Britt Jensen: Similar initiatives are in fact being put in place in other municipalities, inspired by Rødovre.

Torben Bjørn Andersen: That is true, but up until now Rødovre has administered the disability council (even) better than many other places are able to. The other municipalities often do not have executive committees. Often politicians manage the committees, thereby making it easier for them to control the representatives from the disability organisations.

Britt Jensen: It is important that you have a council which does not throw various papers, tasks and regulations at one another. The council is about cooperation. To be effective the council must also be able to take action. That means that the disabled persons must themselves take control. Together with the fact that only one actual politician and a number of adminis-

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Britt Jensen



trators on a management level are members of the council, the executive committee has created a very proactive council in Rødovre.

How do things work when you have two different hats on – that is, you are a member of the disability council while at the same time sitting on the municipal council ?

Britt Jensen: In practice you really take on the role of communicator and act as a liaison between the municipal council and the disability council.

What is required for the cooperation within the disability council to work?

Torben Bjørn Andersen: The most important thing is to a great extent the chemistry between the people on the council. That you respect the position of the politicians and civil servants and do not turn up with a mentality that just wants to make demands. Sometimes you can just see that there is no solution, while there are other times when you are talking about trifling details. Then you have to find a compromise in one place and get something somewhere else instead. That is also the way to gain influence. Not by getting onto the politicians and waving a rule book at them all the time, but by aiming for the most important things and letting go of the trifling matters.

Britt Jensen: Mutual respect and understanding of the other side's situation. Empathy is needed – that is the fundamental thing when you are dealing with people. You also need to have the desire to put

down markers and to be visionary. To really be dedicated to making a difference locally. In many ways it is the same things that lead you to go into politics in the first place.

A disability council has the right to be heard and the right to speak, but it does not have a mandate to take decisions. How does this work in practice? Are you able to see signs of your influence on a decision-making level?

Torben Bjørn Andersen: Yes – they listen to us and our contribution is seen as being significant. On my desk there is a hearing on the health inspectors' visit to care homes in the municipality. The disability council also comments on these. This is the way in which you fully participate in society even though you have a disability.

Britt Jensen: When we in Rødovre say right to be heard, what we mean is influence. We have created a decision-making process that is short. A good example of this could be seen a while ago when the executive committee wished to make it possible for disabled people to have a coordinating contact person to create coherence between the many actors that a family with a disabled member come into contact with. We got that pushed through.

Torben Bjørn Andersen, do you think that you are heard in (all) relevant matters?

Torben Bjørn Andersen: Yes – in areas where we must be heard we are and we get things changed. One of the major themes for us is



accessibility and there can be challenges here for different reasons. The town hall in Rødovre is designed by Arne Jacobsen and it is listed in every possible way. It is not possible to move a screw without making a written application to the Heritage Agency of Denmark. Most recently we have received self-service in the lift that leads into the building. That is a great step forward as you can drive into the town hall yourself without depending on others.

How do you experience the effect of the UN convention in practice?

Torben Bjørn Andersen: Not very much yet. Until now we have worked in accordance with the standard rules for accessibility, also known as DS 3028, and they are quite adequate. This code of practice has been implemented in most places; but the convention goes a step further and has consequently not been implemented yet. It is good that the convention places us in an even better position in regard to full participation in society, but we also had fine rules previously, so we have therefore not experienced a great difference – yet. I expect the convention to be implemented during the next 4–5 years

Britt Jensen: In connection with the drawing up of the current disability policy in Rødovre we have already taken into account and stated objectives in accordance with it - even before the ratification - as we expected it to be ratified. As with so many other things full implementation takes time; but a document like the convention means that it is more difficult to get away with things for those who attempt to do so.

About disability councils in Denmark

www.kommunalehandicapraad.dk
www.handicapraad.dk

Facts

The disability council advises the municipal council on questions of disability policy and is heard in connection with all local policy initiatives that have a bearing on people with disability. The disability council may take a question of more general character up to discussion and present proposals for both political and administrative initiatives.

A disability council does not have a mandate to take decisions, but acts as an advisory organ for the municipal council. Each disability council has 3–7 members from disability organisations within the municipality appointed in accordance with recommendations from Danish disability organisations. The municipal council appoints a corresponding number of members.

A study published in 2009 by the Danish Ministry of Social Affairs showed that 80% of the council members who were interviewed deemed that the disability councils succeeded in getting hearings for relevant initiatives and that politicians and administration subsequently followed their hearing statements. The disability councils are assessed as being a great success that both strengthens the dialogue between the municipal council, the municipal bodies and the local disability organisations, and increases the influence of persons with disabilities on local policy decisions.

Nordic pressure influences national policy

Karen J Klint, chair of the Nordic Council on Disability Policy, wants Nordic politicians to support one another in charged political issues such as welfare technology. What is to be done to ensure that the technology is used for the good of the individual and not just to save money?

We literally meet in the winding corridors of power. Karen J Klint leads the way to her office in one of the wings of Christiansborg Palace in Copenhagen. She is a Social Democrat member of the Danish parliament and this is her workplace. One of the things she pushes for politically is that anyone should be able to work here, irrespective of functional capacity. That is not how it is today.

"Many meeting rooms do not have induction loops. People in wheelchairs can come into the Assembly Room but not use the rostrum. It has been said that it will be sorted out the day that someone is elected who needs it", says Karen J Klint and smiles wryly. All the same, on the way to her office Karen J Klint points to a stair

lift and says that there nevertheless have been some adjustments. Recently she even won a small personal victory.

"Flats are going to be bought for members of parliament to stay in overnight. I got through that at least one flat should be equipped so that you can live there whether or not you have a disability."

Karen J Klint says that working with the Nordic Council on Disability Policy has provided support to her.

"Soundings were taken at Nordic level about the possibility of working on a party-political basis. The parties got to answer as to whether there should be meeting rooms that everyone can access, whether there should be sign language interpreting, etc. This attracted attention and made it easier to push issues in the Danish parliament as well.

Robots to feed people

We have now reached Karen J Klint's office. She has laid on tea, biscuits and a bowl of sweets. We can both help ourselves to what we like but it is not like that for everyone. Karen J Klint tells a story about a disabled man whose wish was for a robot to feed him.

"Then he could eat when he wanted without being dependent on anyone else - it is not an unreasonable wish to have. But on the other hand I can see all too easily the danger of robots feeding people in homes for the elderly,

Facts

The work of the Nordic Council on Disability Policy involves policymaking and providing advice. The Council should be putting important issues relating to disability policy on the Nordic and national political agenda. The Council should also provide support and a source of knowledge to the Nordic Council of Ministers' different sectors that work towards incorporating the disabled perspective into operational strategies and future plans. The Council counts among its members parliamentarians and representatives of the disability movement from the whole of the Nordic region.

instead of them having human contact. It saves money but human beings become more lonely.

Karen J Klint sees robots that feed people as a good example of the dilemma over welfare technology and technological aids for people with illnesses and disabilities. She views it as an issue that would be useful to pursue jointly in the Nordic countries.

"You could take a joint decision in the Nordic countries that welfare technology must emanate from the needs of individuals, not from finances. It would be good if we could pursue charged issues such as this at a Nordic level. I think it is necessary for the survival of the Council."

Karen Klint also believes that together the countries can take a look at what research is necessary regarding welfare technology and carve up the research areas.

"We do not need to invent everything single-handedly. I was in Iceland myself and got to see the artificial legs they make so that people can run rather than just walk. I arranged for the same thing in Denmark."

Too little happening

Karen Klint has spent a long time in Christiansborg now. She has been in parliament since 1998 but she also had a long working life behind her before entering politics. She trained as a social educationalist and has worked with people with intellectual, social and mental disability. Her next job was as centre director of Sønderparken Hornsyld, a centre for social psychiatry in Jutland.

Many of the issues she pushes now as a politician are among those that engaged her at work. She believes that conditions for disabled people have improved in many ways.

"Things are moving forward but progress is too slow. The question is whether perhaps the disability

movement is not too patient. But you cannot say that they are doing anything wrong; the answer lies with us politicians."

One issue that she is involved with at the moment is that the Ankestyrelsen (National Social Appeals Board) is to an ever increasing extent dealing with appeals from local authorities. What it is about is that local authorities do not want to provide disabled people in their area with different types of support, such as have been accorded them by lower decision-making bodies. The National Social Appeals Board is the final court of appeal in terms of welfare issues. It tries cases that are interesting in terms of legal principle.

"The National Social Appeals Board's main function is to ensure that citizens are treated according to the rule of law. But increasingly the National Social Appeals Board has been taking the local authorities' perspective. It will be interesting to see how things have developed in the other Nordic countries. It may be an issue that is best driven forward jointly," says Karen J Klint.

More systematics

She thinks that political work could be more systematic.

"In the Council we could make more use of the knowledge centres that exist in the different countries. If we are going to discuss psychiatry, for example, we should have had contact with the psychiatric knowledge centres before the meeting. I also think we should have more direct contact with the central disability councils."

Karen J Klint says that there is strong political unity in the Council. What can be developed further is how political goals should be reached.

"At the moment what happens is that we get wound up about an issue without always thinking it through. That is something that we can improve," says Karen J Klint.

Karen J Klint asserts: "When we work together across the Nordic countries, issues acquire more weight than when they are only driven forward on a national basis."



A paradigm shift

As a result of the UN Convention on the Rights of Persons with Disabilities, we are shifting the challenges facing disabled people from being a personal health and social issue to an issue concerning the violation of human rights.



"Physical accessibility is something which is just as important as having access to information, communication and electronic services. It is of absolutely fundamental importance so that people can participate in society on an equal footing and exercise their democratic rights," says Karin Andersen, an MP from Norway's Social Left Party (SV) and deputy leader of the Standing Committee on Labour and Social Affairs.

“It is an incredibly important convention. It provides a new direction and way of thinking, in fact, a totally different starting point for equality and anti-discrimination policy,” says Karin Andersen. She is a Norwegian MP from the Social Left Party (SV) and deputy leader of the Norwegian Parliament’s Standing Committee on Labour and Social Affairs.

The Convention, which was adopted by the UN General Assembly in 2006, has been signed by Norway, but has still not been ratified. Some countries were extremely quick in ratifying the UN Convention, making the Convention a declaration of intent which requires long-term effort in order to be achieved. In general, UN conventions must be ratified by a certain number of countries to be able to come into force. This is why some countries do this very quickly.

Putting legislation in place first

“In Norway we want to have legislation in place first, which complies with the Convention. In 2009 the Norwegian Act for the prohibition of discrimination on the ground of disability came into force. Its objective is to dismantle barriers facing disabled people, which have been created by society, and to prevent new ones. The Norwegian Guardianship Act also came into force recently (see the text box on page 70) and we are currently working on drafting a law on the right of access to goods and services.”

Andersen mentions the US where an anti-discrimination law has been in force for many years and the right of access to goods and services also exists. Stores must be accessible so that people with visual impairments can also access the available goods. Even if item information is printed in Braille, a blind person will not be able to remember where all the items are, which means that it is the store’s duty to assist people

with visual impairments in finding them. Consequently, providing a universal model is not sufficient to achieve equality. If people with mobility impairments are unable to enter the store, staff must take the items out to them. This is how it works in the US, as far as Andersen is aware.

A long way to go

Introducing legislation is one thing, but the framework supporting the legislation must also be explained and regulations must be drafted. For example, who is going to enforce the law and what will the consequences be if it is breached? Norway has the Equality and Anti-Discrimination Ombud whose job is to receive complaints relating to the Norwegian Anti-discrimination Act and enforce the new legislation. If you visit this agency’s website, you can see which issue has received the most complaints and gain an overview of the current situation.

“A great deal of work is carried out in Norway’s local authorities on producing universal solutions, but not nearly enough by far. We have a long way to go,” says Andersen.

“Physical accessibility is something which is just as important as having access to information, communication and electronic services. It is of absolutely fundamental importance so that people can participate in society on an equal footing and exercise their democratic rights. Making information available presents a major challenge nowadays. For instance, there is little information available in audio format, Braille and in an easy-to-read format. The whole spectrum of disabilities needs to be covered so that everyone can receive information on an equal basis.”

Putting an end to discrimination in Norway

“In Oslo 90% of places where people can go are inaccessible to wheelchair users. I don’t under-

stand how we can put up with this situation. If women or people from a foreign ethnic group were excluded in this way, there would be a public uproar. We say that everyone is entitled to participate in every area of society, provided that physical accessibility is not involved. There is a widely held public view that disabled people cannot demand total accessibility and they need to lower their expectations. It has proved tough combating this attitude. We expected this to be the case. This is why the policy must concern non-discrimination and equality. The Anti-discrimination Act is meant to put an end to discrimination in Norway. However, even if we don't deliberately discriminate against disabled people, it happens in practice. There are large areas of public life where disabled people are excluded. They will not be turned away by the police, but they cannot get through doors and up stairs!"

Andersen believes that we need to put an end to the idea that disabled people cannot think themselves, are unable to learn anything, don't work and can't make decisions about their own lives. "Everyone is entitled to be able to

participate in society under the same conditions. This must be our starting point."

Costly process

The reason why we accept the lack of physical accessibility is obviously very much to do with the fact that accessibility costs money, so much money in fact that it is not something which can happen overnight. Andersen quotes the railway sector as an example.

"We can buy train carriages providing accessibility, but what good is this when the platforms are the wrong height? We have introduced an EU standard so that all platforms should be at a particular height. It takes time for platforms in every station in the country to be adapted to this standard. Until this is achieved, you cannot be sure, if you are a wheelchair user, that you will actually be able to get off the train, even though the carriage you are in accommodates you perfectly. Who wants to take the train when the situation is like this?"

This is probably the reason why we see so few wheelchair users on the train and elsewhere in public too. There are restricted to a few areas of public life for getting about.

"It provides, at any rate, a popular argument when local authorities are looking for an exemption from the Norwegian Planning and Building Act and want to get round the 'accessibility for all' requirement. 'We don't have any disabled people working for us' is the argument raised. I believe that a tight clampdown is needed on granting exemptions. Local authorities must become more restrictive. We are talking about enforcing a fundamental value," says Karin Andersen.

The Norwegian Guardianship Act

This law applies to people under guardianship and their entitlement to conduct legal proceedings themselves and manage their own finances. It also applies to guardians for people under guardianship and to their powers in terms of conducting legal proceedings or managing finances on behalf of the persons they are guardians for. The law also applies to guardians for minors only if their powers are not covered by parental responsibility under the Norwegian Children Act.

Websites

www.lovdاتا.no

www.fn.no

www.regjeringen.no



From users



Mogens Wiederholt – we are now involved in a battle for resources and raising awareness

Mogens Wiederholt was head of the Equal Opportunities Centre for Disabled Persons in Denmark for 15 years.



"It is primarily people with mental disabilities who may encounter prejudice, otherwise the battle is more about gaining a share of resources," says Mogens Wiederholt.

A forum for dialogue between the disability movement and decision-makers in Denmark.

"The Centre is a thorn in the side of the authorities, but one which people don't want to do without."

It is pure chance that Mogens Wiederholt became involved with disability issues.

When he was called up to do his military service, he chose to do community service and ended up dealing with support equipment for disabled people. This gradually led on to him taking up a position of trust as head of the Equal Opportunities Centre for Disabled Persons. He worked there for 15 years before he became director of the Danish Spastics Association last year.

High-profile civil servant

Mogens Wiederholt is very well known within the disability movement, but he takes care to point out that he is not the person who is in charge of disability policy. During the 15 years he worked at the Centre he was a civil servant employed at the Executive Committee's request. The Centre is answerable to the Danish Ministry of the Interior and Social Affairs, but can act independently. It is the Executive Committee which makes the decisions. It is made up of senior government officials and representatives of the disability movement. According to Mogens Wiederholt, the Executive Committee makes a very positive contribution.

"The members of the Executive Committee abandon their usual roles and will only work to achieve the centre's objective, which is to establish equal treatment. Anyone who usually represents people with visual or motor impairments must abandon this role, while officials are not there to represent the govern-

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ment, but to provide help through their expertise. Anything said by individuals at meetings goes no further.

Another important task the Centre has is to examine, document and analyse the situation in areas where disabled people are at risk of not receiving equal treatment.

"It is not only about highlighting problems, but also about proposing solutions," says Mogens Wiederholt.

The Centre has been instrumental in politicians and the authorities being on the receiving end of criticism, but they have also received support from the Centre for doing something about it. Mogens Wiederholt believes that this is why, in spite of everything, people want to have the Centre, even though it can sometimes feel like an annoying thorn in the side.

Apart from the Centre's obvious mission, it also has a large unofficial influence.

"This is to do with timing. Our contacts in the ministry ensure that we know what is going on. It means that we can provide politicians with material when a particular issue is topical. For example, if we know that there is going to be a school reform, we supply material about special schools so that they are included in the school reform."

Positive change of attitude.

Mogens Wiederholt looks back with satisfaction at the 15 years he spent at the Centre.

"A positive trend has developed during this period and the Centre has been involved in it. There has been a change of attitude. Part of the battle is obviously still about disabled people being accepted and about having an entitlement, which has been achieved to a large extent. The battle now involves increasing knowledge about the conditions disabled people have to put up with and obtaining resources."

In his new job at the Danish Spastics Association, Mogens Wiederholt is urging local authorities

to become aware of the conditions people with cerebral palsy are facing. "Many of our members have cognitive problems, but fail to receive the support they need. This is due to a lack of knowledge and the local authorities being squeezed financially."

Members of the Spastics Association include not only people who are confined to bed, but also people who are doctors and lawyers.

"It is those with plentiful resources who must take action on behalf of the others as well. This is the way it has always been, but it has been even more apparent in recent years. The disability movement has adopted a professional approach so that it can uphold its own interests. There are many others who are also fighting to get hold of public resources. If we are going to operate on an equal footing with politicians and officials, we need to maintain high standards ourselves," says Mogens Wiederholt.

He believes that disability organisations in Denmark have been very successful in avoiding putting each other out of business, and even join forces when necessary.

"We have an umbrella organisation (Disabled People's Organisations – Denmark) which sees to it that the issues concerning all organisations are promoted. They operate in a professional manner."

Mental disability faces toughest battle

People with mental disabilities find it hardest to get their voice heard. They also face the most negative attitudes. Part of the problem is down to the absence of strong organisations representing them. Few want to participate in getting themselves organised.

"If you have had your leg amputated, the simple fact is that you won't get your leg back again. But someone who is mentally ill can receive treatment, which means they are no longer ill. They then don't want to belong to the disability movement."

Although Denmark has ratified the UN Convention on the Rights of Persons with Disabilities, it also needs to have a body to monitor compliance with the Convention. Discussions are on-going about how to do this and also about how it may affect the Equal Opportunities Centre.

“Good will can result in inaction”

“Good will can result in inaction. It wouldn’t do any harm if there were disagreements over disability policy.”

This is the view of Ingrid Burman, chairwoman of the umbrella organisation, the Swedish Disability Federation, and former chairwoman of the Swedish Parliament’s Committee on Social Affairs.

Ingrid Burman has changed workplace, moving from the grand parliament building in Stockholm’s old town to the suburb of Sundbyberg, north of Stockholm. After spending more than 10 years as a Left Party MP, she is now chairwoman of the Swedish Disability Association. One of her key tasks in her current job is to arouse an interest in disability issues among politicians. This is no easy task.

“These issues are not on the agenda at all. One blatant example of this is the very high unemployment rate among disabled people. This gets no mention at all in the debate. All the talk is about young people and immigrants.”

Ingrid Burman believes that the lack of interest among politicians is down to the fact that there is no differentiation between the parties’ disability policies. There is no conflict between the parties on this issue, which means that no one has anything to gain from debating it. According to Ingrid Burman, when politicians meet representatives of the disability movement, they simply convey good will, but not very much happens afterwards.

“This good will can have a devastating effect.”

Did she herself do any better when she was a politician? What is definitely clear is that she was committed to this issue.

To see this, you can search the Swedish Parliament’s database for the actions implemented by the Swedish Parliament’s Committee

on Social Affairs which she chaired between 1998 and 2006 and the motions which were tabled. These included motions on rehabilitation, priorities in the provision of care and measures preventing violence against women with disabilities. One of the most important decisions made during her time as a politician was the national action plan “From patient to citizen”. This was adopted 10 years ago. Ingrid Burman wishes that she and her fellow politicians had taken a different course of action.

“We made a huge mistake by not setting any secondary objectives. I believe that we politicians had blind faith that the plan would be implemented as we had a common desire to achieve this,” says Ingrid Burman.

Secondary objectives needed

She does not remember either the disability movement pushing for secondary objectives.

“I think that they were also very pleased that there had been a change of approach, so that they didn’t really feel either that any further action was required.”

This year, 2010, is when the action plan objectives are meant to be achieved.

“The objectives are still good ones, but it is annoying that we haven’t made further progress.”

Sweden has now undertaken to comply with many of the points featured in the plan with the ratification of the UN Convention on the Rights of Persons with Disabilities.

“We are now focusing very much on the UN Convention. We are running a project which is precisely to do with this, called ‘Agenda 50 – verktyg för våra rättigheter’ (Agenda 50 – tool for our rights).”

UN Convention

In the Preamble to the UN Convention on the Rights of Persons with Disabilities it states that those who have undertaken to comply with the Convention consider that disabled people should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.

The figure 50 represents the number of articles in the Convention and the project's objectives will include providing support to the local disability movement. Numerous articles in the Convention depend on local authorities and county councils assuming their responsibility.

The UN Convention stipulates that those representing disabled people must be involved in issues relating to the Convention's implementation. Ingrid Burman explains that user participation was a key issue for her when she was a politician. She now feels that a covert process is going on leading to a decline in democracy. The disability movement is receiving fewer state subsidies and has less influence.

"The situation wasn't perfect before, but things are going backwards now."

Ingrid Burman gives some examples of this. There was no representative for disabled people included in the newly founded rehabilitation board and substitutes in the delegation for the disabled can only attend if permanent members are not present.

"I don't think that this is a deliberate policy. It is more about people thinking about the need to be more efficient and effective."

Greater use of media

No matter the reason, Ingrid Burman believes that the disability movement must now focus more on promoting their issues in a different way, not least via the media.

Often when disabled people are involved in the media, they are concerned about one particular issue, such as being unable to travel on a train or a withdrawn benefit. They rarely get involved with interest politics.

"But this is not because we don't have any constructive proposals. It's about what the media are most interested in," says Ingrid Burman.

The last year has also seen an increase in the competition for grabbing attention. A new agency



has been set up called "Lika Unika" (Equal Unique). It comprises five associations including organisations for children and young people with visual, hearing and motor impairments. In a Lika Unika press release it states that disability issues are no longer just about welfare, but also concern human and civil rights. This means that we also have to find together new methods for influencing society and a new way of operating. Ingrid Burman definitely agrees with this and hopes and believes that it will be good to establish cooperation.

"There is no opposition within the disability movement. If anything, it is quite the reverse. There is considerable consensus, where the only differences concern the emphasis placed on various issues."

Focusing on common issues

Ingrid Burman has a great deal of responsibility to bear as the new chairwoman of the Swedish Disability Federation. It involves her both establishing cooperation with external agencies and reaching agreement internally on which issues must be promoted collectively. The 39 organisations which form the Swedish Disability Federation are very diverse. For example, the question is whether a patient with kidney disease has anything in common with someone confined to a wheelchair.

"They certainly do. What they have in common is the barrier to accessibility and full participation. This can mean for kidney patients that they are forced to stay in their own local authority to receive dialysis, while for those in wheelchairs, it means that they cannot get about."

Ingrid Burman herself has rheumatism. Full participation means for her that she will not be prevented from working full time, even when there are times when she is feeling unwell.

"Being able to manage my work schedule and change meetings

allows me to work full time. If I had worked anywhere else I might have had to go off sick. This example highlights that it is not about the individual but about the adaptability of the environment."

Facts

The disability policy action plan "From patient to citizen" was adopted in 2000 and is valid up until 2010, involving every area of society.

The national disability policy objectives are as follows:

- creating a community of citizens based on diversity
- forming a society where disabled people of any age can fully participate in the life of that society
- ensuring equal living conditions for girls and boys, women and men with disabilities.

According to the action plan, activities relating to disability policy must be focused in particular on:

- identifying and removing barriers preventing disabled people from participating fully in society (top priority is given to barriers which can be easily removed, making local traffic and public administration accessible)
- preventing and combating discrimination against disabled people
- providing children, young people and adults with disabilities with the wherewithal to enjoy independence and self-determination. (Source: Swedish Government)

From research



DISABILITY RESEARCH

From medical factors to living conditions

Over recent decades a social science perspective of life with disabilities has evolved. This trend requires more knowledge of disabled people’s circumstances and of the working of welfare schemes.

“The issues have changed to reflect this development. We also see this in terms of the concepts involved. We used to focus before on the actual disability and spoke about blind people, deaf people etc. The development of welfare schemes has laid the basis for a better understanding and for the ambition to organise such things as housing, education and work. The concept of handicap became too narrow. We nowadays talk about people with disabilities. Today’s social science research has its origins in the welfare state,” explains Jan Tøssebro, a professor in the Department of Social Work and Health Science at the Norwegian University of Science and Technology in Trondheim.

Need to tackle injustice

In the 1990s a five-year research programme was launched with the aim of acquiring knowledge of policy-related and practical significance to disabled people’s everyday lives concerning practical problems, inequality, living conditions and terms for participation. Medical issues were predominant previously. The spotlight was on causes, incidence and treatment, while the social science aspects played a modest role. Nowadays research is focused less on the specific health aspects. Disability organisations have played a significant role precisely in shifting the research focus from medical matters to living conditions and inequality. The Norwegian Federation of Organisa-



“The agenda is dictated by matters other than research results, but they have a role to play once the agenda has been set,” says Jan Tøssebro.

tions of Disabled People highlighted early on the lack of research into living conditions and was looking for research related to key policy objectives such as equality and participation. The social science research launched in the 1990s uncovered and documented social problems and unacceptable disparities, and also that some groups

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were lagging behind. It was a wake-up call to the politicians: something had to be done!

Research takes off

In 2000 the report "Fra bruker til borger" (From user to citizen) (NOU 2001:22) was published. It indicated that the knowledge base for disability policy was too poor and viewed research as part of what was called mechanisms for bridging the gap between the objectives and reality. The point was to identify circumstances and living conditions which are not politically acceptable, precisely to ensure that something would be done. NOK 50 million was invested in a five-year research programme launched in 2004, which was allocated via the Research Council of Norway.

"This input allowed much more information to be recorded and in more areas than before. New topics were raised, such as aesthetic matters and support equipment. Part of the research included an analysis of the schemes operating in Norway in relation to those in other countries. Legislation also came under scrutiny, which resulted in a broader public debate. The agenda is dictated by matters other than research results, but they have a role to play once the agenda has been set."

Not enough to document the situation

Many studies were inspired by what is known as opposition research. This kind of research uses the explicit ideals of the welfare state to criticise the current state of affairs. The scope of the research ranged from people who were doing well to vulnerable groups which were not doing so well.

"Opposition research presents society and politicians head on with society's own ideals and focuses on the weak points and social problems. This is just as relevant today. We need to highlight social disparities so that we can make progress. This is the rationale behind the

statement: 'the myth that we have a welfare state and compassionate society has made it difficult to establish a compassionate society'. Debunking this myth makes an important contribution to further progress. It means that it is not enough to identify social problems and difficulties. The research must support the available mechanisms and help come up with solutions to: what is happening, why, and what needs to be done.

"Don't get me wrong, it IS good to highlight problems, but we must repeatedly ask why, take a look at what other countries are doing and see what we can learn from them. It doesn't help matters to have yet another study showing the great gap between ideals and reality," says Tøssebro.

One important prerequisite for making progress is to have environments which can conduct disability research on a more stable and permanent basis.

"We must build on our previous knowledge. We need the knowledge we already have to prevent us from losing our way and looking stupid again. Stable provision of funding creates research environments which are built up gradually brick by brick and evolve. This provides a sound basis for developing new knowledge, not to mention establishing international cooperation."

What is happening in the workplace?

"The biggest challenge nowadays remains finding out what is going on in the workplace and in terms of employment policy. How effective are the measures for getting disabled people into the workplace? The assessments made of these measures are positive, but this has not led to an increase in numbers in the workplace overall. When it comes to anti-discrimination measures, public procurement, accessibility and equality, it is too early yet to assess the results of the new legislation. But soon it won't be too early any more."

Research on children will provide better conditions



6

From
research

TEXT: Magnus Gudnason, Louise Hertzberg
PHOTO: Kablonk! RM

5,000 children are being studied in Denmark in a major long-term study. This provides the opportunity of comparing conditions for children with and without disabilities. The researchers have found that a surprisingly large proportion of children placed in care have disabilities.

The researchers have been able to show how children placed in care differ from other children - thanks to the study of children's development that is underway in Denmark. The study is also to be used to gain knowledge about whether children with disabilities who live at home have different life conditions than other children.

In Denmark the study of children's development began in 1995 for children born in that year. These 5,000 children have been followed ever since then. Thanks to the study the researchers and society can gain knowledge about

how children are by and large getting on in Denmark; but the study can also be used to compare the situation for special groups.

Children in care are one such group. All children in care born in 1995 have also been followed and a study has now been presented by Danish researchers at SFI - The Danish National Centre for Social Research (The report is titled the Health and Schooling of Children Placed in Care; Developments after the Reform of Placement in Care). One of the results of the study is that it can be seen how much more usual it is for these children to have

disabilities.

Data on the children was first collected in 2003, when the children were seven years of age, and most recently in 2007, when they were eleven. The study from 2007 also included information from other sources. The children themselves were able to answer questions; the person with responsibility from the social authorities (the case worker) and the places of care could also do so.

Among children in care it is much more usual that they have a diagnosis or a recognised chronic condition. This was the case for 30 percent, while the same proportion among 11 year old children who were not in care was significantly lower at 7 percent. At the same time it turned out that while the majority (69 percent) of children who were not in care but who had a diagnosis only had one diagnosis, around half (47–51 percent) of the corresponding children in care had - both as 7 and 11-year-olds, more than one diagnosis. At the same time, this also applied to children at risk. In other words, children who were placed in care were not only more often subject to long-term illness and disability; the weight of the problem was also greater.

What can this information be used for? The researchers have used the results to categorise the children in care, where they take into account whether the child has disabilities. The researchers do not have documentation for being able to say that the children receive the support they need, but they did discover that the case worker's picture of the children's needs did not correspond with their own analyses - and neither did it correspond with the answers from the places of care. This gave rise to the question of whether the case worker has thorough enough knowledge of the child's situation

and whether there is the necessary dialogue between the places of care and the case workers and for that matter also other involved parties (schools etc.) concerning these children, of whom so many clearly wrestle with problems. The researchers have used the results to categorise the children, where they take into account whether the child has disabilities.

The researchers write that there is a need for greater awareness of the children's disabilities.

Based on the knowledge we have of the field concerning children and young people placed in care, our impression is that children in care are often viewed through a 'social' frame of reference. A 'mental' dividing line appears to exist with differentiation between, on the one hand, the children where action is taken due to social causes and, on the other hand, those who receive help due to reduced ability to function. This study suggests that the picture is more mixed and this in turn raises the question of whether there has been sufficient attention paid so far to the fact that quite a large part of the children in care appear to have difficult preconditions for being able to manage, precisely because their ability to function is reduced.

The knowledge produced by the study has already been taken into use, says Steen Bengtsson, Senior Researcher at SFI - The Danish National Centre for Social Research.

Organisations for children

"Parents associations for children with disabilities reckoned that there should be different codes of practice for children who were placed in care due to social problems and for children with disabilities; we found that this was not possible. Separating the groups is not an option as elements from both sides are present in many cases."

The researchers believe that their results show that there is a need for more knowledge about the relationship between disability and placement in care.

The researchers write:

Is it the case that children with disabilities have a greater risk of being exposed to neglect and abuse? Is disability a consequence of neglect? Does the occurrence of disability in children mean that the threshold for nursing and care is lower?

The researchers will perhaps know more about these questions once they have processed the results of another study that is aimed at children with disabilities. 1,200 children with disabilities were interviewed, as were their mothers. The children were born in 1995, which means it is possible to make comparisons with the children in the major study.

Steen Bengtsson believes they will find that it is more common for children with disabilities to come from families that have social problems.

– We know that various forms of abuse increase the risk of having a child with disability.

The families who participate in the study have been found through the use of municipal registers of families who receive income subsidies because they have children with disabilities.

– This subsidy is received by all types of families, so I cannot see any risk of an incorrect social distribution in the material, says Steen Bengtsson.

He does not have knowledge of equivalent studies where it has been possible to compare children with disabilities to other children.

– We are now able to gain a lot of new information. For example; is it the case that it is more common for children with disabilities to be bullied?

FACTS SFI

SFI is an independent national research centre placed under the Danish Ministry of Social Affairs.

SFI is the largest Danish research environment in the area of welfare and works closely with the strongest professional environments at the various universities. SFI carries out tasks in part on its own account and in part in accordance with contracts with ministries, municipalities and organisations. Contracted tasks make up around half of SFI's annual turnover. Disability policy is one of the areas of policy in which SFI conducts research: Developments in disability and its distribution among the population and its significance for men's and women's participation in education, business, civil society etc. Impact of policy, schemes and administration in general and with regard to specific target groups.

6

From
research

The UN Convention

The UN Convention on the Rights of Persons with Disabilities

In Article 23, Respect for home and the family, it is made clear that children shall not be separated from their parents against their will, except when competent authorities subject to judicial review determine that it is for the best interests of the child. A child may not be removed from its parents on the basis of a disability of either the child or one or both of the parents.

Nordic ideals in Iceland

For Iceland the Nordic welfare model is the ideal. In his research Professor Stefán Ólafsson has been able to demonstrate areas where Icelandic disability policies do not live up to the Nordic model. This has led to improvements for persons with disabilities.

Professor Stefán Ólafsson of the University of Iceland is both sociologist and economist. He has published a number of books in which he uses statistics to compare welfare in Iceland with how it looks in the rest of the Western World and the Nordic countries.

“In Iceland people have a shared perception that the Nordic welfare model is good. We compare ourselves with it because we are part of it,” says Stefán Ólafsson.

Stefán Ólafsson has written a number of books that have been significant for disability policy and welfare in general. In 1999 *Íslenska leiðin* («The Icelandic way») was published, which was about how the Icelandic welfare model could be reformed.

– It had a great deal of influence on the debate.

In 2005 *Örorka og velferð á Íslandi og í öðrum vestrænum löndum* (*Disability and Welfare in Iceland in an International Comparison*) was published. It created a lot of debate. A Google search returned 6,570 hits alone for the Icelandic title. Many of these hits are from newspapers, ministries, disability associations, the Icelandic parliament and trade unions. In addition the English title provides 138 hits. There are also many hits in other contexts where the title is not named. The debate has also led to a number of improvements for persons with disabilities.

Stefán Ólafsson describes himself as a neutral scientist, but other people catch onto what he writes

and make use of it.

“The book *Disability and Welfare in Iceland in an International Comparison* was utilised by *Öryrkjabandalagið* (the association of Icelandic disability organisations) to influence politicians. The book was criticised politically, but it has subsequently influenced politics anyway.”

Stefán Ólafsson makes use of statistics from OECD and the Nordic Social-Statistical Committee (NO-SOSKO). In this way he can show item by item where Iceland is on the same level as the other countries - and where Iceland has fallen behind. He can also show where it is incorrect to say that Iceland follows the Nordic welfare model.

He could for example show that disability pensions were lower in Iceland compared with the rest of the Nordic countries and that many of the people who received pensions also bore a heavy taxation burden. He also showed that rehabilitation for young people with disabilities was less directed at working. Stefán Ólafsson could show cases which did not fit into the Nordic welfare model as Iceland had a lesser degree of income equalisation and social exclusion was higher among young people as there was less support to help young people find work.

“Since the book was published, disability pensions have increased, the tax burden has been reduced and more rehabilitation aimed at working.”

Stefán Ólafsson believes that the



Nordic comparisons are an important part of Icelandic research and politics.

“And it is probably the case that you emphasise the things that are not working but do not say so much about the things that work.”

There are areas where other countries compare themselves with Iceland and wonder how we manage to do things. This is first and foremost true of participation in the

labour market. OECD statistics from 2007 show that Iceland is right at the top when it comes to participation in the labour market.

“The Icelandic population work long hours and there are many older people with disabilities who do not receive any pension but who work instead. That at any rate grabs the interest of researchers in the other Nordic countries,” says Stefán Ólafsson.



Professor Stefán Ólafsson

In the Scandinavian countries there are a number of research institutions carry out research that affects people with disabilities and disability policy. Some of them are mentioned briefly below.

Finland

- The National Institute for Health and Welfare (THL) promotes social inclusion, accessibility and special services and support measures. THL also manages statistics on disabilities. www.thl.fi
- The Rehabilitation Foundation (Kuntoutussäätiö) carries out research, assessments and development in public health, social care and nursing services, work and rehabilitation. www.kuntoutussaatio.fi
- The University of Jyväskylä carries out research in the fields of sociology and social sciences with focus on disabilities, special education, neuropsychology, rehabilitation, disability sport and exercise for the disabled. www.jyu.fi/edu
- The unit for disability research at the University of Kuopio carries out research centred on social areas and society. www.uku.fi/english
- The Finnish Association on Intellectual and Developmental Disabilities (FAIDD) studies the quality of municipal services and rehabilitation and researches into the living conditions of people with intellectual disabilities. www.kehitysvammaliitto.fi

Denmark

- The Danish National Centre for Social research, SFI, is Denmark's largest research environment in the field of welfare. One of the areas covered by SFI is policy for the disabled. www.sfi.dk
- The Danish School of Education, Aarhus University researches among other things into education for target groups with special needs. www.dpu.dk
- The Danish Institute of Governmental Research, AKF, researches into topics concerned with public service. www.akf.dk
- The Social Development Centre SUS works with development, assessment and implementation of methods to improve the quality of life of its users. www.sus.dk/

Sweden

- The Universities of Linköping and Örebro collaborate at the interdisciplinary Swedish Institute for Disability Research (IHV). www.ihv.se

- The HAREC – Disability and Rehabilitation Research Centre promotes and coordinates scientific projects. www.harec.se
- Certec projects include work to make technology user friendly. www.certec.lth.se
- The Centre for Disability Research at Umeå University is an interdisciplinary network that also includes practical training. www.socw.umu.se/centrum-for-handikappvetenskap/
- The Centre for Disability Studies at Uppsala University is a collaborative organisation for researchers at the different faculties at Uppsala University. www.cff.uu.se

Norway

- The Work Research Institute researches into areas such as inclusive work life. www.afi.no
- Nordland Research Institute studies reduced function and society, and also aspects concerned with civil rights. <http://nordlandsforskning.no/>
- The Centre for Public Policy Innovation (CPPI) at Lillehammer University College and the Eastern Norway Research Institute (ENRI) research into user-controlled personal assistance and empowerment. www.hil.no och www.ostforsk.no
- Norwegian Social Research, Nova, was nominated a Nordic Centre of Excellence in Welfare Research, for the period from 2007 – 2011. This includes researchers from the whole of Scandinavia. One of the themes at the centre is policy for the disabled with focus on exclusion and participation. www.nova.no och www.reassess.no.
- The Research Council of Norway is running the project “IT funk – IT for the disabled”, which researches into accessible IT. www.itfunk.org

Iceland

- The Centre for disability studies is an interdisciplinary research centre which is concerned with people with impaired function. <http://vefsetur.hi.is/fotlunarfraedi/>
- The State Diagnostic and counselling Centre in Iceland researches among other things into autism, using resources such as the unique gene bank in Iceland. www.greining.is

6

From research

International overview



Human rights activist



Jukka Kumpuvuori with his colleagues in Kampala. Representatives of the association for persons with spinal injuries.

"The hot topic of conversation globally on disability matters is the UN Convention on the Rights of Persons with Disabilities. Nothing can be done on disability policy without referring to the Convention," says Jukka Kumpuvuori, a researcher at the Institute for Human Rights at the Åbo Akademi University in Turku, Finland.

The UN Convention on the Rights of Persons with Disabilities has been relevant since 2001 when Mexico proposed the Convention under the auspices of the UN. The Convention was adopted by member states in 2006.

"There is nothing new about the content of the Convention itself. But it has raised the profile of and specifically mentioned rights for the disabled," says Kumpuvuori.

Many countries, including Uganda, have been quick to ratify the Convention. Among the Nordic countries, both Sweden and Denmark have ratified it. This process is still going on in Iceland, Finland and Norway.

"This is a matter of cultural difference. Some countries carry out the ratification process quickly and do not ask how everything will work in practice, while other countries, like Finland, make

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amendments to laws, which takes time and lengthens the process,” explains Kumpuvuori. Kumpuvuori is an activist and researcher. He works on several issues concerning people with disabilities and human rights both in Finland and abroad. He developed an interest in these issues while he was a student when the inaccessible physical environment, such as stairs up to lecture halls and social events, prevented him from taking part in activities as he moved around in his wheelchair. Kumpuvuori became motor-impaired when he was 10 due to cancer of the spine.

Jukka Kumpuvuori has a large number of international contacts. He is seen here with his research colleague Edson Ngirabakunz in New York.



International law

Kumpuvuori is currently doing research into what a ban on discrimination and equivalence in international law mean from the perspective of the situation in Uganda. He is interested in three specific issues: equality and non-discrimination, distribution of resources based on international human rights standards and, lastly, the repercussions of international and national laws for disabled people and organisations working with the disabled. His research will lead to a doctoral thesis.

According to Kumpuvuori, the problem in Uganda is that there are many fine laws and administration programmes, but they are not put into practice. In Uganda human rights are violated and there is discrimination. At the same time, there is a powerful civil movement which champions the cause of the disabled.

Need to learn to make demands

The problem in Uganda is that it is not only a matter of resources but of attitude as well. Kumpuvuori believes that disabled people must learn themselves to demand what they need. This is not only the case in Uganda, but worldwide too.

There are proportionally more disabled people in developing countries than in industrialised countries. This is due to there being fewer protective factors. Accidents, war and undernourishment caused by poverty are all factors contributing to the development of disabilities.

Kumpuvuori visited Uganda as recently as March this year and was involved in organising a course on human rights and disabled people at Makerere University in Kampala.

“The problems encountered by disabled people are the same all over the world, but the solutions to them are different,” says Kumpuvuori.

In Uganda, just as in many other places in Africa, support for disabled people is based on charity. In practice,

it is disability organisations which are responsible for disability issues.

“And when charity is involved, you cannot, as a disabled person, demand any rights,” adds Jukka.

The UN Convention has helped raise awareness about disabled people. At the same time, organisations in Uganda have fared better in obtaining funding from abroad.

There are pros and cons to the systems used in various countries. For example, in the US the system is based on everyone having to have insurance. Employers are often responsible for the insurance, but it is more difficult, if you are disabled, to go out to work. However, the US has more stringent anti-discrimination legislation than Finland. A comprehensive social service system is available in the Nordic countries.

“Finland is admired in the rest of the world for its social service system, in other words, the Nordic welfare model, if we can still actually talk about such,” says Jukka.

Convention provides self-confidence

The UN Convention on the Rights of Persons with Disabilities has given disabled people greater self-confidence. This is perhaps its most important function, in Kumpuvuori’s view. He also believes that disabled people themselves must demand their rights. They must ask for the physical environment to be made accessible, for instance, for a ramp to be built for the local kiosk. Disabled people must not be content to be excluded. Some years ago Kumpuvuori got his employer to install a lift so that he could get to his office by himself.

In Kumpuvuori’s view, in future, society can no longer adopt a passive stance towards disabled people. If we want to have a non-discriminating society, we must actively work to make everything accessible for disabled people as well.

The UN convention

The UN Convention on the Rights of Persons with Disabilities is among the key human rights conventions. This Convention was adopted by the UN General Assembly on 13 December 2006. As of 20 May 2010, 144 states had signed the Convention, including all the Nordic countries. 86 states had ratified the Convention, including Sweden and Denmark. The other countries which have ratified it are scattered all over the world. They include, for instance, China, Germany, India, Malawi, Uganda, Tanzania and Brazil.

Once a state has ratified the Convention, thereby undertaking to comply with it, it is legally binding. To ratify a convention, a country’s legislation needs to conform to the requirements stipulated by a convention. This also applies to how the laws are enforced. The ratification process is under way in many countries. Signing the Convention is often the first step towards its ratification.



Useful information

Website links

Nordic information/institutions

- The Nordic Council on Disability Policy
www.nordiskahandikappolitiskaradet.org
- Nordic Centre for Welfare and Social Issues
www.nordicwelfare.org
- Nordic Social-Statistical Committee
<http://nososco-da.nom-nos.dk/>

Organisations for persons with disabilities

- Disabled People's Organisations – Denmark
www.handicap.dk
- Norwegian Federation of Organisations of Disabled People (FFO)
www.ffe.no
- Cooperation Forum of Disability Organisations (SAFO)
www.safo.no
- Swedish Disability Federation
www.hso.se
- Organisation of Disabled in Iceland (ODI)
www.obl.is
- Icelandic National Association of Intellectual Disabilities
www.throskahjalp.is
- Association of Voluntary Health, Social and Welfare Organisations (YTY)
www.sosteryty.fi
- Federation of Swedish-Speaking Disabled in Finland
www.handikappforbundet.fi

Equality ombudsmen

- Equality and Anti-Discrimination Ombud
www.ldo.no
- Equality Ombudsman
www.do.se

Miscellaneous

- Equal Opportunities Centre for Disabled Persons
www.clh.dk
- Swedish Agency for Disability Policy Coordination
www.handisam.se
- National Council on Disability VANE
www.vane.to
- Information about the UN Convention
www.un.org/disabilities/



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Fra bruker til borger – en strategi for nedbygging av funksjonshemmende barrierer (From user to citizen – a strategy for dismantling disability barriers). NOU 2001:22 (Norway)

Från patient till medborgare – en nationell plan för handikappolitiken (From patient to citizen – a national disability policy plan). Prop 1999/2000:79 (Sweden)

Handikappråd – en chans att påverka eller ett spel för gallerierna? (Disability councils – a chance to have an impact or merely window-dressing?) Institute for Local and Regional Democracy. 2007 report 5. (Sweden)

Handikapplagen LSS och annan närliggande lagstiftning (Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (Disability Act) and other related legislation)

Karl Grunewald and Carl Leczinsky, sixth edition, 2008, Norstedts juridik (Sweden)

The UN Convention on the Rights of Persons with Disabilities. DS 2008:23 (Sweden)

Främja, Skydda, Övervaka – FNs konvention om rättigheter för personer med funktionsnedsättning (Promote, Protect, Monitor – UN Convention on the Rights of Persons with Disabilities) SoU 2009:36 (Sweden)

En politik för det civila samhället (A policy for civil society) prop 2009/10:55 (Sweden)

Ett samhälle för alla (A society for all). Ministry of Social Affairs and Health, National Council on Disability 1995:10 (Finland)

Nationella system för förmedling av hjälpmedel (National system for the provision of assistive technology) – second edition NUH May 2007 (Nordic)

Nordic Statistical Yearbook 2006 (Nordic)

Kumpuvuori, Jukka, Högbacka Marika Mänskliga rättigheter för personer med funktionshinder i Finland (Human rights for persons with disability in Finland), Ministry of Social Affairs and Health reports 2003:10, Helsinki (Finland)

Möjlighet att leva som andra Ny lag om stöd och service till vissa personer med funktionsnedsättning (Chance to live like others. Second Act concerning Support and Service for Persons with Certain Functional Impairments). Final Report of Disability Act Committee. SOU 2008:77 (Sweden)

Lär känna FN:s Konvention om rättigheter för personer med funktionsnedsättning (Getting to know the UN Convention on the Rights of Persons with Disabilities). Document from the project Agenda 50 – verktyg för våra rättigheter (Agenda 50 – tool for our rights). Swedish Disability Federation, SRF (Swedish Association of the Visually Impaired), SVERI (Swedish Committee of Rehabilitation International), Forum – Women and Disability in Sweden supported by the Swedish Inheritance Fund (Sweden)

Social trygghet i de nordiske lande 2004 (Social security in the Nordic countries 2004), NOSOSCO 2006 (Nordic)

Handikapperspektivets synlighet inom fem politikområden (Profile of the disability aspect in five policy areas). NSH 2004 (Nordic)

Från Vision till verklighet – En utvärdering av nationell handlingsplan för handikappolitik (From vision to reality – An assessment of the disability policy national action plan). Swedish Agency for Public Management 2009-21 (Sweden)

Handicap som krydsfelt (Disability as a crossover point), Danish Disability Resource Centre 2009 (Denmark)

Funksjonshemming – politikk, hverdagsliv og arbeidsliv (Disability – policy, everyday life and workplace). Tøssebro, Jan (editor) 2009 (Norway)

Staden för alla (Making the city accessible to all)– Grip – Nordic Disability Policy Council 2009 (Nordic)

Statsrådets redogörelse om handikappolitiken 2006 (Finnish Government report on disability policy 2006), Ministry of Social Affairs and Health 2006:10 (Finland)

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Summary



Summary

The Nordic countries have had a leading role in the development of the UN Convention on the rights of persons with disabilities. Now that the convention has been agreed upon by the UN, the great work of living up to the requirements of the convention remains.

In order to do so, a well-planned disability policy is required. Traditionally, the Nordic countries have cooperated on these issues. This theme publication is part of that cooperation. The texts are intended as an inspiration and a source of knowledge, we learn from each other. The theme publication can of course also function as an inspirational source outside the Nordic countries.

At the beginning of the theme publication there are basic facts on Nordic disability policy. Here, it clearly shows how many similarities there are between the countries, especially with regard to eliminating differences of life conditions for people. At the same time, there are interesting differences.

The Nordic countries have in common that they do not have highly developed levels of judicial testing. This means that people can demand their rights in a court of justice. Many researchers believe that there is going to be a development towards higher levels of judicial testing.

In the chapter "From real life" interesting examples from the Nordic countries are presented. Among other things, one can read about experiences from Norway, which was the first Nordic country to pass laws prescribing requirements for accessibility to public buildings, also including state enterprises.

Finland has excelled by being the only country in the world to decide that people with problems of speech have a right to an interpreter. This has given new insights into how much these people have to contribute if they get help communicating.

In Iceland, people have also gained new insights thanks to a project on university education for

people with learning difficulties. Ása Björk, who was in the first group of students, thinks the most valuable lesson learnt from the education is the understanding of how much she is able to do herself.

Ása Björk got a job after her studies. Otherwise, unemployment is a big problem among people with disabilities. Working life researcher Øystein Spjelkavik wants to see many more job coaches, people who are present and provide support in the workplace. Doing research on working life and disability is popular now. Research has moved from a focus on medical matters to matters relating to life conditions and possibilities of participation in society, according to Jan Tøssebro, professor at the Department of Social Work and Health Science at the Norwegian University of Science and Technology in Trondheim.

A great deal of the work of promoting disability issues and of implementing the UN Convention on the rights of people with disability must be done at a local level, in the municipalities. It is common practice in the Nordic countries to have disability councils with the participation of local politicians and users. In Denmark, this is a fruitful collaboration. A politician and a user representative from the Rødovre municipality explain that real user influence is an important prerequisite, as is the will to cooperate.

At Nordic level, politicians cooperate within the Nordic Council on Disability Policy. Chairman of the Council, Karen J Klint, tells that in the case of issues at a Nordic level, it is easier afterwards to promote political matters at a national level, no country wishes to be inferior to others. Similar experiences are to be found in Iceland. Researcher Stefán Ólafsson made a scientific comparison of the conditions of people with disabilities in Iceland and the other Nordic countries. The comparison showed, among other things, that Iceland to a lesser degree made income adjustments for people

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with and without disability. It led to a debate and to improved conditions for people with disabilities.

The theme publication finishes off with a glance at the outside world. Jukka Kumpuvuori is an activist and researcher at the Institute for Human Rights at Åbo Academy in Finland. His research is on the consequences of international and national laws for people with disabilities and disability organizations in Uganda. The problems people with disabilities face are similar all over the world, but the solutions to them are different, Kumpuvuori states.

In this theme publication, we stress the successes of Nordic disability policy, and also areas where further action is needed. We also make a few recommendations that we hope will contribute to reaching the high standards set for disability policy by the Nordic countries: that people with disabilities can be fully integrated in society.

The Nordic Centre for Welfare and Social Issues recommends that:

- An increased Nordic cooperation is supported nationally in order to coordinate cooperative work on the UN convention. The Nordic countries can also use a common Nordic profile at Conferences for States Parties to the UN and within the EU.
- Labour market policy aims to facilitate diversity and to allow more people with disabilities to

enter working life and to stay in their new employment. Job coaches have proved to yield good results. It is a matter of stimulating and lowering the thresholds for vulnerable groups in order to reduce exclusion. This holds true for youths, groups and persons with disabilities, immigrants and elderly employees. Better cooperation between school/educational institutions and working life is needed.

- Inaccessibility or lacking accessibility to environments, goods and services, and to information technology, should be evidence of discrimination.
- Universal design should be the basis for all society planning, central and regional and in the municipalities. This applies to both public and private companies, entrepreneurs and other activities.
- User organizations should have appropriate space and representation in the decision process at different levels, centrally, regionally and in the municipalities.
- Disability research should get the resources and freedom to create new knowledge, useful to the involved staff groups in various sectors of society, but also useful in a Nordic context for the development of disability policy.

Tiivistelmä

Pohjoismaat ovat vauhdittaneet vammaisten henkilöiden oikeuksia koskevan YK:n yleissopimuksen valmistelua. Nyt kun YK on päättänyt yleissopimuksesta, jäljellä on suuri työ vastata yleissopimuksen vaatimuksiin.

Tämä vaatii harkittua vammaispolitiikkaa. Pohjoismaat ovat perinteisesti tehneet yhteistyötä näiden asioiden parissa. Tämä teemavihko on osa yhteistyötä. Tekstit on tarkoitettu innoitukseksi

ja tietopohjaksi, toinen toisiltaan oppimiseen. Teemavihko voi tietenkin toimia innoituksen lähteenä myös Pohjoismaiden ulkopuolella.

Teemavihko alkaa pohjoismaisen vammaispolitiikan taustatiedoilla. Niistä tulee selvästi esiin, miten paljon yhtäläisyyksiä maiden välillä on, varsinkin ihmisten elinoloissa olevien erojen tasoittamista koskevissa kysymyksissä. Samanaikaisesti löytyy mielenkiintoisia eroja.

Pohjoismaille on yhteistä, ettei oikeusajattelu ole kovinkaan vahvasti kehittynyt. Toisin sanoen, ihmiset voivat vaatia oikeuksiaan tuomioistuimissa. Monet tutkijat uskovat kehityksen menevän siihen suuntaan, että oikeusajattelu lisääntyy.

Luvussa ”Från verkligheten” esitellään kiinnostavia esimerkkejä Pohjoismaista. Siitä voi lukea muun muassa, miten asiat ovat sujuneet Norjassa, joka ensimmäisenä Pohjoismaana asettaa lainsäädännössään esteettömyysvaatimuksia yleisille tiloille, myös niille, jotka ovat kaupallisia.

Suomi on kunnostautunut maailman ainoana maana, joka on tehnyt päätöksen puhevammaisten ihmisten oikeudesta tulkkien. Tämä on antanut uutta tietoa siitä, kuinka paljon näillä ihmisillä on sanottavaa, jos he saavat apua itsensä ilmaisemiseen.

Islannissa on myös saatu uutta tietoa kehitysvammaisten ihmisten yliopistokoulutusta koskevan projektin ansiosta. Ensimmäiseen opiskelijaryhmään kuuluneen Åsa Björkin mielestä koulutuksen tärkein anti oli saada itselleen käsitys siitä, kuinka paljosta selviää.

Åsa Björk on saanut koulutuksen jälkeen työpaikan. Työttömyys on muuten suuri ongelma vammaisten ihmisten keskuudessa. Työelämä-tutkija Øystein Spjelkavik haluaa nähdä paljon useampia työvalmentajia, tuetun työllistymisen ohjajia, jotka ovat mukana tukemassa työpaikoilla. Ajan henkeen kuuluvat työelämää ja toimintarajoitteita käsittelevät tutkimukset. Tutkimusten keskiö on siirtynyt lääketieteellisistä kysymyksistä asioihin, jotka koskevat elinoloja ja mahdollisuuksia osallistua yhteiskuntaan, kertoo Jan Tössebro, Trondheimissa sijaitsevan Norjan teknis-luonnontieteellisen yliopiston sosiaalityön ja terveystieteen laitoksen professori.

Suuri osa vammaistyön edistämisestä ja vammaisten henkilöiden oikeuksia koskevan YK:n yleissopimuksen toteuttamisesta on tehtävä paikallistasolla, kunnissa. Pohjoismaissa on tavallisesti vammaisneuvostoja, joissa istuu paikallispoliitikkoja ja käyttäjiä. Tanskassa tämä yhteistyö sujuu

erittäin hyvin. Rødovren kunnan poliitikkojen edustaja ja käyttäjien edustaja kertovat, että tärkeä edellytys on käyttäjien saama todellinen vaikutusvalta ja yhteistyöhön asennoituminen.

Pohjoismaisella tasolla poliitikot tekevät yhteistyötä Pohjoismaisessa vammaispoliittisessa neuvostossa. Neuvoston puheenjohtaja Karen J Klint kertoo, että kun kysymyksiä ajetaan pohjoismaisella tasolla, on helpompi saada poliittiset kysymykset läpi kansallisella tasolla, sillä mikään maa ei halua olla muita huonompi. Samankaltaisia kokemuksia on Islannista. Tutkija Stefán Ólafsson teki tieteellisen vertailun vammaisten ihmisten elinoloista Islannissa ja muissa Pohjoismaissa. Vertailu osoitti muun muassa sen, että Islannissa oli vähemmän tulontasausta vammaisten ja vammattomien ihmisten välillä. Tämä sai aikaan keskustelua ja paremmat elinolot vammaisille ihmisille.

Teemavihkon päättää kansainvälinen katsaus. Jukka Kumpuvuori on Åbo Akademin ihmisoikeusinstituutin tutkija ja aktivisti, joka tutkii kansainvälisistä ja kansallisista laeista vammaisille ja vammaisjärjestöille koituvia seurauksia Ugandassa. Vammaisten kohtamat ongelmat ovat samanlaisia joka puolella maailmaa, mutta ongelmien ratkaisut ovat erilaisia, toteaa Kumpuvuori.

Pohjoismaisen vammaispolitiikan saavutusten lisäksi nostamme teemavihossa esiin myös alueet, joihin on panostettava enemmän. Annamme myös suosituksia, joiden toivomme edesauttavan Pohjoismaiden vammaispolitiikalle asetettujen korkeiden tavoitteiden saavuttamista: että vammaisilla ihmisillä tulee olla täysi osallisuus yhteiskunnassa.

Pohjoismainen hyvinvointikeskus suosittaa, että:

- Lisääntynyt pohjoismainen yhteistyö saa kansallista tukea YK:n yleissopimusta koskeviin maidenvälisiin kokoontumisiin. Pohjoismaat voivat myös tuoda esiin pohjoismaisen profiilin YK:n valtio-osapuolten välisissä konferensseissa sekä EU:ssa.
- Työmarkkinapolitiikka vaikuttaa monimuotoisuuteen ja siihen,

- että useimmat vammaiset ihmiset pääsevät työelämään ja voivat pysyä aloittamassaan työsuhteessa. Työvalmennuksesta on saatu hyviä tuloksia. Syrjäytymisvaarassa olevia ryhmiä on innostettava ja kynnyksiä alennettava, jotta ulkopuolisuus vähenisi. Tämä koskee nuoria, vammaisryhmiä ja vammaisia henkilöitä, maahanmuuttajia, ikääntynyttä työvoimaa. Tarvitaan parempaa yhteistoimintaa koulun/koulutuksen ja työelämän välillä.
- Ympäristöjen, tavaroiden ja palvelujen sekä tietotekniikan saavuttamattomuuden tai puutteellisen esteettömyyden tulee olla syrjäntäperuste.
 - Kaiken yhteiskuntasuunnittelun,

kansallisen, alueellisen ja kunnallisen, tulee perustua kaikille sopivaan yleispätevään suunnitteluun. Tämä koskee sekä julkista että yksityistä toimintaa, urakoita ja muita hankintoja.

- Käyttäjäjärjestöille annetaan asiaankuuluva paikka ja edustus eri tasojen päätösprosesseissa, kansallisella, alueellisella ja kunnallisella tasolla.
- Vammaistutkimus saa resursseja ja liikkumavaraa uuden tiedon tuottamiseen, joka on hyödyllistä eri yhteiskunta-alojen asiaankuuluville henkilöstöryhmille ja josta on hyötyä myös pohjoismaisesti vammaispolitiikan kehittämiseksi.

Samantekt

Norðurlöndin hafa verið í fararbroddi við innleiðingu sáttmála Sameinuðu þjóðanna um réttindi fatlaðs fólks. Nú þegar sáttmálinn hefur verið samþykktur af SP stendur eftir hin mikla vinna við að uppfylla kröfur sáttmálans.

Svo að það megi vera unnt þarf til meðvitaða stefnu í málefnum fatlaðra. Á Norðurlöndunum er hefð fyrir samstarfi um þessi málefni. Þetta þemahefti er liður í því samstarfi. Textarnir eru hugsaðir sem innblástur og grundvöllur þekkingar, við lærum hvert af öðru. Þemaheftið getur að sjálfsgöðu líka nýst sem uppspretta innblásturs utan Norðurlandanna.

Í byrjun þemaheftisins eru settar fram staðreyndir um norræna stefnu í málefnum fatlaðra. Stefan sýnir á skýran hátt hve margt er líkt með löndunum, ekki hvað síst þegar kemur að jöfnun lífsskilyrða fólks. Um leið má finna áhuga-verðan mismun.

Það er sameiginlegt með Norðurlöndunum að ekki er til sérlega vel þróuð réttarhugsun. Með því er átt við að fólk geti barist fyrir rétti sínum fyrir dómstólum. Margir fræðimenn telja að þróun muni eiga sér stað í áttina að aukinni réttarhugsun.

Í kaflanum Úr daglegu lífi (Från verkligheten) eru sett fram áhuga-verð dæmi frá Norðurlöndunum. Þar má meðal annars lesa um hvernig tekist hefur til í Noregi, sem var fyrst Norðurlandanna með lagasetningu sem gerir kröfur til aðgengis að opinberu húsnæði, að meðtöldum ríkisreknum viðskipta-fyrirtækjum.

Finnland á heiður skilinn fyrir að vera eina landið í heiminum sem hefur ákveðið að fólk með talmeini eigi rétt á túlki. Það hefur veitt nýja innsýn í hve mikið þetta fólk hefur fram að færa ef það fær aðstoð við að tjá sig.

Á Íslandi hefur fólk einnig opnast ný sýn fyrir tilstilli verkefnis um háskólanám fyrir einstaklinga með þroskaskerðingu. Ása Björk, sem var í fyrsta nemahópnum, telur að mikilvægasti þáttur námsins hafi verið að hún gerir sér nú grein fyrir hve mikið hún getur sjálf.

Ása Björk fékk vinnu að loknu námi. Annars er atvinnuleysi útbreitt vandamál meðal einstaklinga með fötlun. Fræðimaðurinn Øystein Spjelkavik, sem stundar atvinnulífsrannsóknir, vill sjá mun fleiri vinnuþjálfara, einstaklinga sem eru til staðar og veita stuðning á

vinnustöðum. Rannsóknir á atvinnulífi og fötlun eru tímans tákn. Áherslan í rannsóknum hefur færst frá málefnum læknisfræði til þátta eins og lífskjara og möguleika á þátttöku í samfélaginu, segir Jan Tössebro, prófessor við félags- og heilbrigðisvísindadeild í Tækniháskóla Noregs í Þrándheimi.

Mikinn hluta starfsins við að vinna að framgöngu fötlunarstarfs og hleypa SP-sáttmálanum um réttindi fatlaðs fólks í framkvæmd verður að vinna heima fyrir, í sveitarfélögum. Á Norðurlöndunum er venjan að nota fötlunaráð þar sem stjórnmalamenn í heimahéraði og notendur taka þátt. Í Danmörku virkar þetta samstarf mjög vel. Einn stjórnmalamaður og einn fulltrúi notenda í Rødovre bæjarfélaginu útskýra að mikilvægt sé að notendur hafi raunveruleg áhrif og að menn séu reiðubúnir að vinna saman.

Á Norðurlöndunum eiga stjórnmalamenn samstarf í Norrænu samstarfsnefndinni um málefni fatlaðra. Formælandi nefndarinnar, Karen J Klint, segir að þegar mál eru tekin fyrir á vettvangi Norðurlandanna, þá reynist auðveldara að koma pólitískum málum í gegn heima fyrir, ekkert land vill vera síðra en hin. Svipaða sögu má segja frá Íslandi. Fræðimaðurinn Stefán Ólafsson gerði fræðilegan samanburð á kjörum einstaklinga með fötlun á Íslandi og á hinum Norðurlöndunum. Samanburðurinn leiddi meðal annars í ljós að Ísland hafði minni tekjujöfnun milli einstaklinga með og án fötlunar. Upp úr því hófust umræður sem leiddu til bættra kjara einstaklinga með fötlun.

Þemaheftinu lýkur með umfjöllun þar sem litið er út í heim. Jukka Kumpuvuori er baráttumaður og fræðimaður við Mannréttindastofnunina í háskólanum í Åbo í Finnlandi og stundar rannsóknir á afleiðingum alþjóðlegra og innlendra laga fyrir fatlaða og samtök fatlaðra í Úganda. Sá vandi sem fatlaðir standa frammi fyrir er svipaður alls staðar í heiminum en lausnirnar á vandanum eru ólíkar segir Kumpuvuori.

Í þemaheftinu beinum við sjónum að því sem hefur náðst í málefnum fatlaðra á Norðurlöndunum, en líka að þáttum þar sem

þörf er frekara átaks. Við setjum einnig fram nokkrar ráðleggingar sem við vonumst til að geti stuðlað að því að við komumst nær þeim háleitu markmiðum sem Norðurlöndin hafa í stefnu sinni um málefni fatlaðra: að einstaklingar með fötlun eigi að standa öðrum jafnfætis í samfélaginu.

Norræna velferðarmiðstöðin mælir með að:

- Aukið norrænt samstarf hljóti innlendan stuðning þegar kemur að samstarfi landa um SP-sáttmálann. Norðurlöndin geta einnig markað sameiginlega norræna stefnu við ráðstefnur aðildarríkja SP sem og innan ESB.
- Stuðlað skuli að fjölbreytni á vinnumarkaði og að fleiri einstaklingum með fötlun skuli gefinn kostur á þátttöku í atvinnulífi og að þeir geti haldið fengnu starfi. Vinnuþjálfar hafa reynst gefa góðan árangur. Það skiptir máli að hvetja og lækka þröskulda fyrir hópa sem minna mega sín í þeim tilgangi að minnka útilokun þeirra. Þetta á við um unglinga, hópa og einstaklinga með fötlun, innflytjendur og aldrað vinnuafli. Samstarf skuli bætt á milli skóla/menntastofnana – atvinnulífs.
- Skort á aðgengi eða slæmt aðgengi að umhverfi, vörum og þjónustu, og að upplýsingatækni, beri að líta á sem mismunun.
- Hönnun fyrir alla eigi að liggja að baki alls samfélagsskipulags, miðlægt, á svæðisvísu og í sveitarfélögum. Þetta á bæði við um ríkisrekin og einkarekin fyrirtæki, verktaka og aðra starfsemi.
- Notendasamtök skuli hafa nægilegt rými og fulltrúavald í ákvarðanatökunni á ólíkum stigum, miðlægt, á svæðisvísu og í sveitarfélögum.
- Fjármagni og tíma skuli veitt í rannsóknir um málefni fatlaðra til að skapa nýja þekkingu, sem er til gagns fyrir þá starfshópa sem koma við sögu í ólíkum samfélagsgeirum og eru líka til bóta fyrir norræna þróun í málefnum fatlaðra.

Contributors from NVC



Lasse Winther Wehner

Information officer,
Master's degree in IT and
Bachelor's degree in
English.

Performs information-gathering and journalistic tasks, including editing, layout, website development, translation and IT-related tasks.



Magnus Gudnason

Academic assistant,
Master's degree in
Danish and English and
a translator.

Performs various information-gathering and journalistic tasks, including editing, simultaneous interpreting, translation, and he maintains NVC's contact network.



Helena Lagercrantz

Information manager
journalist, graduated
from the Humanities
programme at Stock-
holm University.

Responsibility for
coordinating informa-
tion at NVC.



Martina Harrikari

Project officer
Master's degree in
sociology.

Provides assistance on various projects at the Helsinki office, mainly relating to alcohol and drugs. Her duties include providing information, making arrangements, as well as administering and coordinating various tasks.



Gerd Vidje

Journalist,
freelance, currently
attached to NVC.
Bio-engineer, journalist,
communication and
management.



Ingemar Oderstedt

*Project manager at the
Nordic Council on
Disability Policy,*
Bachelor's degree in
sociology.

Works with the Council
and its six networks.



Louise Hertzberg *PR
officer*

journalist, Bachelor's
degree in political
science

Works on gathering
information and
journalistic assign-
ments.



Nordic Centre for Welfare and Social Issues

The Nordic Centre for Welfare and Social Issues – an institution under the Nordic Council of Ministers

We seek to stimulate development and clarify different aspects of the Nordic welfare model.

The aim of our work is to promote the inclusion of vulnerable groups, with equality, social solidarity and also accessibility and quality in issues connected with social services.

The three main objectives of the Nordic Centre for Welfare and Social Issues

Knowledge

We gather and coordinate experience from the Nordic countries in the field of welfare policy.

Dissemination

We pass on knowledge and experience of good examples through our activities and network.

Dialogue

We set up dialogues between politicians, researchers and field workers.

Our work covers the following areas:

- Alcohol and drug issues
- Inclusion in the labour force
- Deaf-blind affairs
- Questions of functional disorder
- Social services
- The welfare model
- Welfare technology

Our organisation

The institute's head office is located in Stockholm, with branches in Denmark and Finland.

The Nordic Centre for Welfare and Social Issues is led by a committee of representatives from the five Nordic countries. The Committee is appointed by the Nordic Council of Ministers.

Our operations are linked to a network of Nordic institutions and experts. Their task is to integrate our work into practice and pass on the results to decision makers and field workers.

A significant proportion of our work is carried on internationally. We collaborate with international players in the health and social area, including the European Union, the European Council and the United Nations.