

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

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Background:

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

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

The purpose of the report (<u>Terms of Reference</u>) is to review national implementation of the open method of coordination in <u>Social inclusion and social protection</u>, and is particular the <u>National</u> <u>Strategic Reports</u> of member states from a disability equality perspective, and to provide the Commission with useful evidence in supporting disability policy mainstreaming.



PART ONE: SOCIAL INCLUSION PLANS (GENERAL)

1.1 Please describe how and where disabled people are included in your country's published plans for social inclusion and protection?

Since Norway is not a member of the EU, there is no requirement to produce National Reports on Strategies for Inclusion and Social Protection within the Open Method of Coordination, and such reports do not exist. However, there are a number of other policy documents addressing exclusion, poverty, social security and long term care. The extent to which disability is explicitly addressed in such documents varies, as it does in all policy documents of relevance to disability in Norway. This could be illustrated by a few recent examples:

In the Action plan combating poverty (AID 2006)¹ disability is hardly mentioned at all. People with mental illness is addressed and unemployed disabled people is indirectly a target group for a new labour marked measure (wage subsidises). It is also claimed that the proportion with long term low income (less than 60% of the median for more than three years) among people with disability benefits, is decreasing. The groups specifically addressed include young singles, immigrants, ex prisoners, people with drug/alcohol problems and children in poor families. Some measures in the action plan will be relevant for disabled people, particularly measures to increase labour marked participation.

In the White Paper on "Employment, Welfare and Inclusion" (2006), there is a chapter on groups at risk that among others include a specific analysis of the labour marked situation of disabled people. Most of the measures proposed are general, but due to the increasing number on disability benefits and the low employment rates of disabled people, the issue is specifically addressed. A recent White Paper on long term care also addresses disabled people (2006), but is criticized from the disability movement to be severely biased towards being a paper on care for elderly people. It is claimed that it does not adequately address the needs of younger people with care needs. A White Paper on Housing Policy (2004) addresses disability. This is however not mainly linked to social exclusion policies, but to the need for more accessible housing. And the income of a substantial group of disabled people is indirectly discussed, obviously, in the Public Committee Report proposing a new system for disability pensions (2007, no 4).

It should be added at this point that the general idea in Norway is that disability policy should be mainstreamed or included according to the principle of sector responsibility. This means that education of disabled people is included in policy documents of education, accessibility to the build environment is included in the building codes, and employment is discussed as part of employment policies. Thus, it is not necessarily a problem that disability rarely are mentioned in the above policy papers, the question is whether disability issues are adequately analysed and addressed when it comes to policy measures. This relates to what is missing from plans, which is a big question. However, in keeping with the Public Committee Report on disability policy strategies (2001, no 22), I would say that the main problem may not be at the ideals, plans or policies level, but on implementation and reality. The ideal-reality gap is too wide and the implementation too half-hearted (cf. also White paper 40, 2003).

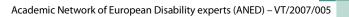
1.2 In reality, what major actions has your country taken and what tare the positive or negative effects on disabled people? (policy or practical examples)

As a non-member of EU, there are no steps involved in the EU Social Inclusion Process to report. However, if looking broader at the issues – one could briefly describe the recent trends in Norwegian disability policy.

¹ <u>http://www.regjeringen.no/upload/kilde/prm/2006/0133/ddd/pdfv/292446-h-plan2006_fattigdom.pdf</u>







The most important changes that have taken place recent years (since 2000) can roughly be described as supplementing welfare/ redistribution policies with regulation policies.

Regulation policies means policies intended to regulate the activities of civil society. This could be building codes, transport regulations, public procurement, etc. This type of policies and measures are far from new in Norway, but they have not until recently been used actively in disability policy – and then mainly to combat discrimination and improve accessibility. Examples of legislation is the implementation of EU directive 2000/78/EC, a new act on discrimination and accessibility of disabled people including specific paragraphs on accessibility to ICT (in operation from 2009), revision of the building legislation, the public procurement act, parts of the transport regulations, etc. This recent trend is largely due to influences from EU, EU countries and the US.

There are few new initiatives regarding traditional welfare policies. The system for disability pensions is likely to be revised as a consequence of a total revision of social security, but this is mainly for fiscal reasons and not to combat poverty or exclusion. One could however note that the political attention to the lack of employment among disabled people is increasing. A scheme for personal assistants has also become operational (it was introduced in 1994 but made part of the Social Care legislation (and thus fully in operation) from 2000, and extended thereafter).

The effects of the above mentioned changes in the practical everyday life of disabled people are as yet uncertain. An evaluation done in 2006 found that most policy changes after 2000 so far had little real life impact (DOK/SHDIR 2006). One should however also notice that evaluations of the personal assistance scheme are very favourable (Askheim 1999).

Disabled peoples' organisations are not directly involved in the policies or the implementation. That would also be contrary to the opposition or watch-dog role of the organisations. However, there does exist a kind of corporate system where disabled peoples' organisations meet and discuss policy issues with representatives of the government. There is also a State council on disability, and by law a disability council in all municipalities/ local governments. Disabled peoples' organisations are represented in these councils.

1.3 What is the most recent research about disabled people's equality and social inclusion in your country?

Frankly speaking, there are few research reports about disabled peoples' equality and social inclusion the last two years. Updated data on labour marked participation, showing that there is no improvement in employment figures does exist (Statistics Norway 2007). There is also some updated data on income and poverty (cf. section 2.1 on this paper).

Hopefully there will be more updated data on equality and social inclusion soon. In 2007/2008 a large scale survey on the living conditions of disabled people was carried out. The first results are expected by the end of 2008. The survey was carried out by Statistics Norway on behalf of a group of researchers in collaboration with the Directorate on Health and Social Affairs and the National Centre for Documentation on Disability. This is the first survey on the living conditions of disabled people since 1995, and it also includes the possibility to scrutinize the consequences for results of different definitions of disability/ impairment.





PART TWO: INCOMES, PENSIONS AND BENEFITS

2.1 Research publications (key points)

The recent research on poverty, income and pensions of disabled people are summarised in two reports (DOK/SHDIR 2006; DOK 2007)². One of the reports is an unofficial 2006 follow-up of a Public Committee Report from 2001 (no. 22), analysing changes in policy and practice during the first part of this decade. The background is as follows: The National Centre for Documentation on Disability and the Directorate on Health and Social Affairs asked eight research groups to address the situation and recent policy/ real life changes on eight life domains: employment, housing, ICT, culture and leisure, education, build environment, transport and private economic situation. The reports are gathered in one volume, accompanied by the unofficial analysis of the 2001 Public Committee (DOK/SHDIR 2006). The main conclusion is that even though there have been a number of new political initiatives during the last decade, the ideal-reality gap is as wide as ever. However, many of the new initiatives have not yet been in operation for very long, some are not even implemented yet (the non-discrimination act is implemented in 2009). Thus, one should not jump to conclusions about ineffectiveness.

The other report is a "State of the nation" report from the new National Centre for Documentation on Disability (established in 2006 and becoming a part of the Equality and Discrimination Commission from 2009). It reports on the same life domains as the above mentioned report, and also on societal participation and health- and social services.

As for the data on income and poverty among disabled people, both reports build on a study by Statistics Norway in 2006 (2006/18), and based on living conditions data gathered in 2002. The key findings are the following: (1) The composition of the income of disabled people differs from that of the general population since fewer are employed, fewer earn money from financial investments, and more people receive social security/ benefits. (2) Adding income from employment, investments and benefits suggest that disabled people have a mean income that is about 75% of the mean income of the total population (in the age group 18-66). (3) If taxes are included in the calculations, the mean disposable income of disabled people is about 80% that of the total population. (4) The gender gap in income exist also among disabled people, but is smaller than in the total population (the mean disposable income of disabled women being 80% that of men). The gap in disposable income gap between disabled and non-disabled people appear to be smaller among young people (younger than 40) than among people aged 40-66. (6) There are no data on the income of disabled people with ethnic minority background.

The data on income differences and sources of income appear to be fairly relevant and reliable. Data on poverty seems to be of a poorer quality, and relates to people receiving disability benefits rather than disabled people as such (which are overlapping but far from identical groups). The Public Committee Report on revised disability pensions (2007, no 4) suggest that about 10% of the people receiving disability pensions experienced long term low income (less than 60% of the median for three subsequent years) in the late 1990s. This was about the same figure as the total population.

Since then the proportion among disabled people with long term low income has gone down (6% in 2004), whereas it is stable among the general population.

²http://web3.custompublish.com/getfile.php/347084.951.pvecqsxbuy/Full+deltakelse+for+alle+del+1.pdf?return=www. dok.no; http://web3.custompublish.com/getfile.php/347086.951.prqbtdsarb/Full+deltakelse+for+alle+del+2.pdf?retu rn=www.dok.no; http://www.dok.no/getfile.php/601863.951.dbdwpvexvb/Statusrapport+07-+Samfunnsutvik lingen+ for+personer+med+nedsatt+funksjonsevne.html; English summary of DOK 2007: http://web3.custompublish.com /getfile.php/601350.951.wuqyrpbbse/Sammendrag+på+engelsk.pdf?return=www.dok.no





With the 2008 increase in the minimum level of pensions (13.75%), one can expect that the proportion of pensioners in poverty decreases.

Other types of poverty measures show a conflicting pattern. On indicators such as domestic possessions, financial problems and poor housing, there appears to be few differences from the total population. However, on indicators such as the number receiving supplementary benefits for poor people (either for accommodation or daily living), disability pensioners outnumbers the total population with a factor of three (about 15 vs. about 5%). This may suggest more poverty, but it may also be because people with social security have easier access to those kinds of supplementary benefits. Disability pensioners are overrepresented among people who claim to have a difficult economic situation, and who cannot afford a week holiday.

In short, the conclusion appears to be that the income of disabled people fall substantially short of the total population, but also that poverty is uncommon.

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

The main pension for disabled people is the disability benefit. Some receive a time limited disability benefit before being granted the disability benefit, but this is now replaced by a general temporary benefit (merged with the rehabilitation benefit). The disability benefit can be claimed by people between the ages 18-67 that have a loss of income opportunities of more than 50% due to long term disease, injury or impairment. Adequate medical and vocational rehabilitation should have been tried without sufficient success.

Many disabled people (with or without disability pension) also receives one or two types of supplementary benefits for people with long term disease, injury or impairment. One of them ("basic benefit") is intended to cover extra costs; the other ("attendant benefit") is to compensate for private service needs (not necessarily expenses). Many disabled people receive the "basic benefit", whereas the "attendant benefit" is more typical for children living with their family. Disabled people can also receive rent support (for accommodation), technical aids, transport, etc. The calculation of the disability benefit is quite complicated, based on earlier income levels and years. People becoming disabled before the age of 26 will have a guaranteed minimum benefit, which from 2008 is 173 500 NOK (21 700 Euro) annually. The general minimum pension is 136 500 NOK for single person households. In 2005, about a third of the full (100%) disability pensioners had 150% of the minimum pension or more. Two thirds had more than 130% of the minimum. About of all full disability pensioners 10% had the minimum pension, a majority being women (Public Committee report 2007:4, page 76). (The time limited disability benefit is based on the same minimum levels, but a simpler calculation (basically 66% of earlier income). The calculation is similar to the rehabilitation benefit.

The "basic benefit" is divided into six annual rates based on needs assessment/ likely extra expenses. The lowest rate is 7000 NOK (900 Euro), the highest 35000 NOK. About 50% receive the lowest rate. People who are granted support for a car as technical aid receive rate 3 to cover running costs (40% of all receive rate 3 or 4, NOK 14-21 thousand). There are four "attendant benefit" rates, from NOK 12 600 to NOK 75 600. People aged 18 or more can only be granted the lowest rate.

The population of Norway is 4 770 000 people. By the end of 2007, 295 000 received the disability benefit and 39 000 the time limited disability pension (totally about 7% of the population). In 2008 about 131 000 people receive the "basic benefit" and 85 000 the "attendant benefit". For details and trends, see appendix.

An English overview over the pension system can be downloaded from: <u>http://www.regjeringen.no/upload/AID/publikasjoner/veiledninger_og_brosjyrer/2008/dnts_eng.pdf</u>.





Further information can be read at (in English): <u>http://www.nav.no/page?id=805312736</u> or (in Norwegian): <u>www.nav.no</u>

2.3 Policy and practice (summary)

The whole social security system in Norway is under revision. This is basically due to two partly linked issues: to create a sustainable financial basis, and to encourage people to work. The aging population is a part of the background, the increasing number on disability benefits or early retirement schemes another. There is proposed a new disability pension (Public Committee Report 2007, no 4). This initiative was not due to a political need to revise the disability pension as such, but in order to avoid some possible unwanted side-effects of the changes in the pension system for senior citizens.

There is also a reform of the employment and social security administration just being implemented. This implies a merger of the two administrations in order to make sure employment is the first and preferred option.

It is an important presumption of the revision of the disability benefits that it should pay to work. People should be encouraged to choose employment as the preferred option if possible. There is also recently introduced a number of ways (or more ways) to combine benefits and employment. The point is to introduce more flexibility in order to avoid disincentives or barriers to employment among people that cannot work fully.

The idea that it should pay to work does not mean that the level of compensation of the disability benefit is under severe pressure. The point is to make more people work (part time or full time) rather than reducing or increasing the level of compensation. Actually the minimum compensation was raised substantially earlier in 2008 (almost 14%), and also the minimum for people becoming disabled before the age of 26. There is however disagreement about the consequences of the "it should pay to work" presumption. The Public Committee proposing a new system searched for situations were people might gain from leaving work in order to rule out possible disincentives to work, whereas disability organisations tend to argue that the "work should pay" presumption in reality is contradictory to the prevailing "equality" ideal in disability policy. If work always pays, it means that not being able to work or being denied the opportunity to work will definitely be punished in financial terms.

Each year disability organisations are involved in formal negotiations with the government on the size of the pensions in Norway, but at the end of the day, the government decides.

The principles of social security for disabled people do basically follow the same set of rules and regulations as the general system, but of course there do exist a disability pension and some benefits solely for people with disability and/or long term diseases – but this is actually a general principle and it does not distinguish between disability and for instance chronic illness (such as cancer) or other legitimate reasons for not being able to work. Incapacity would maybe be a better translation of the principle behind the benefits, actually also the Norwegian term for the benefit (ufør), rather than disability.

The question of whether the income of disabled people who cannot work is sustainable is open to debate. It rarely leads to poverty, but the level of compensation challenges the ideals of equality and full participation. The question of whether the financial system could cope with the increasing number of people that do not work is also open to debate. The fiscal situation of Norway is sound, but nevertheless, the pension system is changed in order to make more people at all ages work more because of possible fiscal threats to the sustainability of the system.



SECTION THREE: CARE AND SUPPORT

3.1 Recent research publications (key points)

In Norway local authorities are responsible for long term care outside hospitals or institutions. During the last two decades one has seen a substantial increase in the number of people aged 66 or less that receive such services (local authority long term care) – 78% increase from 1995 to 2005 (SHdir 2007). This development has been analysed in a recent report by Romøren (2006). He identifies two large and two smaller groups of service users. The two large groups are people with mental illness and people with severe somatic conditions, mainly neurological (such as MS, stroke, brain injuries). The two smaller groups are people with intellectual disabilities and people with drug/alcohol problems.

The main reason for the increasing number appears to be deinstitutionalisation. Institutions for intellectually disabled people were replaced by community care in the early 1990s, local mental health services has expanded and included living arrangements (programme from 1999-2008), and there is also the trend towards shorter stays in all kinds of hospitals, nursing homes and institutions.

Few people under the age of 67 receive long term care in institutions or nursing homes in Norway today. This type of care is considered an unwanted option. However, some young people are in nursing homes. The central government has implemented a number of programmes to combat this, but it seems like when one person is successfully transferred to community care, another person is admitted. The total number aged under 67 in nursing homes is nevertheless few.

Another important report addresses the current services for people with intellectual disabilities (Breivik and Høyland 2007). Key findings are included in the description under section 3.2.

There is in general a need for updated research on the quality of community care, not least with regard to people with intellectual disabilities and people with mental illness.

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

Norway was the first country to close all institutions for intellectually disabled people (early 1990s). This also indicates the general policy regarding institutions as a system of care. Institutions are regarded as unwanted, and even though one does not speak much about normalization anymore, this ideology has a strong position. Thus, community care is clearly preferred. The type of care can be illustrated by the services for intellectually disabled people. When institutions closed, most people resettled in group homes with 3-5 residents. Each individual were offered an apartment in this group home, consisting of a bedroom, sitting room, kitchen and bathroom. It was about 50 square meters and deemed adequate according to the National Housing Banks regular standards for one person households. Some people did not resettle in group homes, but independently. The size and standard of the unit was nevertheless about the same as units in group homes. Others (although few) resettled in sheltered housing, where the other residents might be elderly people, people with physical disabilities or metal illness. Even the individual units in sheltered housing were of about the same size and standard as in the group homes.

Services are partly provided "in house" and partly ambulatory (from a remote service centre). Most people rent units/apartments from the local authorities. In principle you can choose were to live yourself, but in practice most will have to accept the option provided by the local authorities.

For other groups of disabled people with substantial service needs, group homes are less common. They tend to live either independently or in sheltered housing. Sheltered housing can be in blocks with quite a lot of people with service needs, sometimes called care containers.







Disabled people with less service needs tend to buy housing on the open marked, even though the availability of accessible housing may be limited.

Personal assistance schemes have been in operation on a preliminary basis since 1994, and became a regular part of social services in 2000. In early years it was restricted to people who was able to act as supervisors themselves, but recently it has also been granted people with cognitive/ intellectual disabilities (in which case parents or guardians has acted as supervisors). It is proposed to enact that people that receive more than 20 hours of care services each week, should have the right to chose to organise the services as personal assistance. It is not yet clear when this will be enacted. The number of people with a personal assistant has gradually increased. In 2005 it was 1 700 people, increasing with about 20% the last 3-4 years.

The funding for personal assistants is public (local with some national support), and the disabled person him-/herself can act as employer. However, it is more common that the municipal authorities or a foundation organised by disabled people (ULOBA, <u>http://www.uloba.no/</u>) act as employers. The person him-/herself typically directs the work/support.

The quality of care and support does only to a very limited extend depend on the person's or the family's own financial resources.

There do exist work rehabilitation services and also support for transport, but this is organised by the national social security system, not the local social and care service system.



PART FOUR: SUMMARY INFORMATION

4.1 Conclusions and recommendations (summary)

Disabled people tend to have low income, but few live in poverty. It is unclear whether an introduction of extra expenses into the calculations will change such a conclusion. The main challenge regarding social exclusion, however, appears to be the low employment rate, which has not changed lately. The long term care services are based on community care provided by local authorities. Normalisation ideology is strong. It is however a need for more research digging into the quality of care.

The situation for disabled people has not changed very much recent years. Going back to the 1990s there were important deinstitutionalisation reforms. The policy initiatives today focus accessibility and non-discrimination, but we are yet to see the results of these efforts (which I think is likely to make a difference gradually during the next 4-6 years, but this is of course dependent on implementation and law enforcement).

If I should highlight one issue of policy importance today, it will be exactly what is mentioned in the paragraph above: To make sure that the implementation of the new initiatives (nondiscrimination and accessibility regulations) is effective. We have seen to many good intentions disappearing in a weak implementation.

4.2 One example of best practice (brief details)

In my opinion many countries can learn from the Norwegian reform for people with intellectual disabilities. It is possible to provide people with adequate community care, living on residential streets and in units deemed acceptable for all people. This goes for people with mild intellectual disabilities, but also for people with severe disabilities and challenging behaviour. Evaluations tend to show that the reform was a clear improvement, even though one did not reach all goals one had hoped for (Tøssebro and Lundeby 2002). The costs of the reform are uncertain. Total expenses saw a dramatic increase, but this was due to the increasing number of people served rather than increasing costs for each individual (which was uncertain but most likely marginal, cf. UK findings). The point is that when community care became a realistic, more people wanted services – and more people were provided services.





4.3 References

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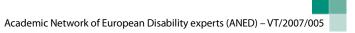
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Appendix:

Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Total	264	275	283	288	297	307	315	324	330	336
Women	151	158	162	166	171	176	181	187	191	194
Men	113	117	120	123	126	130	134	137	140	142
Age 18-29	8	8	8	8	8	8	8	9	10	10
Age 30-49	71	74	75	75	76	78	80	83	85	86
Age 51-59	92	97	101	105	109	112	113	113	112	110
Age 60-67	93	95	98	100	103	108	113	119	124	129
100% disability (%)	79	79	79	79	79	79	80	80	80	80

Table 1. Number (in the mande) of manual with dischility newsion of temperature dischility

* Level of disability is graded from 0-100 dependent on assessed ability to work. 100% disability means that you receive a full disability pension (according to what you are entitled to) because you are not able to work.

Table 2: Number of people (thousands) with basic benefit and attendant benefit, 1999-2008											
Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	
Basic	130	130	132	133	133	134	134	132	131	131	
benefit											
Attendant	89	89	90	90	90	89	87	87	86	85	
benefit											

