



ANED country report on the implementation of policies supporting independent living for disabled people

Country: Norway

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PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

The principle of normalisation has been politically supported by the Norwegian government for decades. In the 1990s this led to the dismantling of the main remaining sector of institutions, institutions for intellectually disabled people. This move was backed by the main organisations for /of intellectually disabled people. Evaluations show that the reform was positive, but also that parts of the community alternatives were more institution-like than hoped for. There are currently worries related to trend in the wrong direction, that is, community care appears to become more congregated and institution-like. However, the most important lesson is that many European countries will have a lot to learn from Norway (and some other countries) regarding deinstitutionalisation and resettlement in the community.

The provision of personal assistance in order to facilitate an independent living for disabled people in Norway is a relatively recent development. It was inspired by our neighbouring countries, Sweden and Denmark; that in turn were inspired from abroad. At the outset, the service was only for people that could act as “supervisor” of assistance themselves. After a change in regulations effective from 2006, one could also have support for this supervision role, which meant that intellectually disabled people also could have personal assistants. The personal assistants scheme is run by municipalities, but a cooperative of disabled people have been quite successful as a provider and facilitator of this service (ULOBA). It is the municipality that decides how services are organised, that is whether it is as personal assistants or by traditional services. There have been moves to give the user more say with regard to this, but so far the governmental proposal is pending (has been postponed several times).

The system for provision of assistive equipment is quite well developed, and is rights based. It has however been criticised for being based on a complicated and bureaucratic application procedure, leading to waiting time and delays, and also lack of self-determination. As a response to this, an arrangement called user pass has been introduced as an option for experienced users since 2006 (piloted from 2004). This means that the user have more responsibility him-/herself in the process of replacing, adjusting and repairing the assistive equipment, and have the opportunity to contact suppliers directly. With this new option, people tend to experience less delays and more self-determination. So far, however, only a minority of users of assistive equipment (typically younger people) have this user pass. The challenge is to develop the new type of procedures in a direction that is applicable for a wider group of assistive equipment users.



PART 2: LEGAL AND POLICY CONTEXT

The principle of normalisation has been politically supported in Norway for nearly four decades. This implies that residential institutions have been regarded as unwanted, but also that generic services and the general legislation should be the basis of the support for disabled individuals. There exist few laws and regulations that specifically targets disabled people and only disabled people.

The general principle adopted in Norway is that the state is responsible for social security (such as disability benefits, actually an incapacity benefit for people “not able to work” (ufør in Norwegian)) and provision of assistive equipment, whereas the local authorities (municipalities) are responsible for services. The main exceptions to this are that municipalities are responsible for a supplementary cash benefit (intended to be short term and based on an assessment of needs) and that the State is responsible for specialised health services (such as hospitals). In legislative terms this means that the personal economic basis for independent living in the community (for disabled people that do not have a job) is the Act on Social Security (Lov om folketrygd, 1997, Feb. 8 last revision, 2009), that also regulate provision of assistive equipment, whereas the most important support services are provided according to the Act on Social Services (Sosialtjenesteloven, 1991, Dec. 13, last revision 2007). The act on Social Services also regulates support and services for people needing long-term care. In addition the Act on Community Health (Kommunehelseloven 1982, Nov. 19, last revision 2009) regulates the provision of some health related services in the community.

The Act on Social Security is based on individual rights, that is, a person eligible for a benefit has the right to the benefit. Services according to the Act on Social Services are rationed.

According to the Act on Social Services, local authorities are responsible for the provision of a) practical support, including personal assistance, to people with substantial needs due to illness, disability, age or other causes, b) respite care, c) leisure activity assistants for people in need of such services due to age, disability or social causes, d) residential care, and e) economic support for people that provide exceptional care for family members. This paragraph regulates the most important services for disabled people that need practical support to live independently in the community. According to another paragraph, the local authorities are also responsible for housing of people that cannot take care of their own interests at the housing market (cannot buy or rent accommodation without help). Many group homes for intellectually disabled people are raised according to these regulations, but typically backed by financial incentives from special State funded housing programmes organised by the State Housing Bank..

Residential care is typically provided in the persons own home (owned or rented) or a group home. Institutions hardly exist, except for nursing homes for elderly people with substantial care needs.

That local authorities are responsible for services and housing, does not mean that it cannot be purchased from private providers. However, this is uncommon in disability services, with some exceptions. The most important exception is personal assistance, where a cooperation run by disabled people (ULOBA) is providing and organising services for many people.

Based on these principles and this legislation, disabled people in Norway live in the community. Some, particularly some intellectually disabled people, live in group homes. Most group homes in Norway consist of units where each person has a full apartment, with bedroom, kitchen, bathroom and living room. Most group homes are on residential streets, but some are criticised for a location near nursing homes or other long term care facilities, thus creating an impressions different from that of a residential area.



It is also open to discussion how independent the living arrangements in group homes are. The personal assistant service is established due to criticisms related to lack of choices and independence in traditional services.

There also exists a system called omsorgsboliger (sheltered housing or care facilities). This is apartments people can buy or rent from the municipality, for people that need support services. It is however not a service system, it is housing. You will have to apply for social services on the same grounds as people living in other types of living arrangements (their own home). You may have few services in an omsorgsbolig, but you can also be provided more services than what is maximum available in a typical private home. Omsorgsbolig is for all people that need services, but the main group is elderly people (when this started it was supposed to be for elderly people that needed extensive services but not nursing homes). This option has however gradually been more widespread for disabled people as well, including people with physical disabilities, intellectual disabilities, mental illness, etc. (Bliksvær 2005). The number of people grouped together in an omsorgsbolig facility tend to be larger than the group homes for intellectually disabled people, and also to have a more diversified group of users. Whereas a typical group home for intellectually disabled people house 3-5 people, an omsorgsbolig could be for 50 people or more but the number varies considerably.

Disabled people have the same legal capacity as other people. However, some adults (mainly with intellectual disabilities) have a semi-guardian expected to support them or act on their behalf in economic and other affairs (for instance legal). These regulations (Act on legal guardian, Vergemålsloven 1927, April, 22, last revision 2003) are under reconsideration in order to fulfil the requirements of the new UN convention. There also exists legislation regulating use of restraint in services for people with intellectual disabilities (amendments to Act on Social Services, chapter 4a of 2003, Dec. 19), . The intention is to counteract the use of restraint by strict regulations of the procedures that must be followed in order to use restraint, and restraint can only be used to avoid significant harm.

The most important policy changes with regard to dismantling of institutions in Norway took place during the 1990s. There are few recent initiatives. There exists a proposal to strengthen the right to personal assistants, but the enactment has been postponed several times (see below). There has also been a programme (from 2003) to provide alternative (community) services for people under 50 years that live in nursing homes (125 people in 2002, see below).

The ideas about normalisation and community living has been around in Scandinavia for decades, and had a number of sources – including professionals (argument: institutions made more harm than good), politicians (the regular service system must be changed in order to be able to serve a wider range of people) and organisations of (or for) disabled people (arguing the case of normal lives and better living conditions). In the process of dismantling the last important sector of institutions, those for intellectually disabled people, the parents' society played a significant promoting role. Disabled peoples' organisations were also important when the personal assistant scheme was imported to Norway (with inspiration from Sweden). In general, disabled peoples' organisations in Norway has supported and argued the case of inclusion and normalisation, with the exception of the deaf (sign language) community that has supported special sign language schools and environments.



PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

In general, the only service option for disabled people in Norway is support and services in the community. The last large sector of institutions, those for people with intellectual disabilities, was closed during the 1990s. This was based on an unanimous decision in the parliament in 1988. The transfer to community care was supposed to take place from 1991 through 1995. In 1990 about 5500 people lived in institutions for intellectually disabled people, about 90% had left by the end of 1995 and by the turn of the century, institutions for intellectually disabled people were history.

It is however the case that a small group of people with severe and most often complex impairments have been institutionalised in nursing homes for elderly people. This has been regarded as an unwanted option, and both in the 1990s and after 2000 there has been efforts to establish community alternatives. This has included an earmarked economic transfer scheme from the state to local authorities. Even though we talk about a small group, the programmes have not been very successful. Actually the number increased from 2002 to 2005 (from 125 to 177 people). More recent data cannot be compared with earlier data because more types of facilities (less institution-like) are included in the figures, SSB 2008).

The overall picture is however that institutions play no role in disability services in Norway, and that cases of institutionalisation are seen as scandals. There is no investment in institutions for disabled people, but as mentioned above, some are placed in nursing homes due to lack of alternatives. See however below on trends in community services.

The reform for intellectually disabled people in the 1990s was followed up by a number of independent evaluations. One important lesson for other countries can be drawn from a long term follow-up of family attitudes (Tøssebro and Lundebj 2006). Even though a majority of parents (nearly 60%) feared the consequences of resettlement in the community, a large majority supported the changes both shortly after relocation and also almost ten years after (75% better or much better, 10% no change, 15% worse or much worse). The overall results from the evaluations are as follows (cf. Tøssebro and Lundebj 2002):

Housing standards was much improved. This was not just a matter of material conditions, but did also have important social implications. For instance was the number of people reported to have conflicts or problem with fellow residents reduced to half of what was reported from institutions. More self-determination was reported on everyday issues such as clothing, leisure activities, food, but no change on issues involving the service administration (such as decision on where to live, and with whom). The frequency of contact with family increased.

In other life domains, changes were less significant, for instance with regard to day-time occupation, social relations (except family), participation in cultural or leisure activities for all people. The main (only) negative finding is a reduction in leisure activities, probably because of the dissolution of the activity centres at institutions.

There is no real study of changes of costs in Norway (comparing costs of community and institutionalised care). At the national level, the costs of community care for intellectually disabled people went far beyond that of institutions. However, the main reason for this is that more people were served. The deinstitutionalisation reform was also a programme for providing residential services for people earlier living with their family. There is no pre-post study of costs of services for identical groups of people. The investment in housing did of course temporarily increase, since a number of new facilities were buildt, but this was investments rather than running costs.



The public debate currently is not about institutions as such, but about community services becoming more institution-like. Recently many cities have established group homes that is housing more people than what was typical of the 1990s. Most group homes established during the first decade after 1991 served 3-5 people. Today one can see examples of group homes for more than ten people. Most such cases follow the established standards (about 50 sqm. with bedroom, bathroom, kitchen, sitting room) with regard to the quality and size of each individual apartment, but the number of people grouped together increases. There is a major conflict between the disability organisations and local authorities around this issue in many cities. This trend is in part related to changes in the state funding of housing arrangements, from a special programme related to the dissolution of institutions for intellectually disabled people, to the system of "omsorgsboliger" described above. This process has not been subject to evaluations or research, thus it is difficult to assess how widespread it is, what the motivations of local authorities are, and also the consequences for service users.

One other trend needs to be mentioned. Today some argue that nursing or institution-like facilities tend to become less institution-like, whereas as community care becomes more institution-like. Some kind of convergence appears to take place. A recent project commissioned by the National Centre for Documentation on Disability is coined "Boliggjøring av sykehjem og institusjonalisering av omsorgsboliger for funksjonshemmede under 67 år" which translates to "making nursing homes more housing like and community care for disabled people below the age of 67 more institution like". Thus, the argument is that the sharp distinction between community care and institutions may tend to become less clear than a decade ago, because of changes in both types of services. The results from the study are however not yet published, thus the evidence base is weak. The change in institutions/nursing homes is however current national policy, whereas worries about the trend in community care has been raised by the association for intellectually disabled people (NFU) in several parts of the country, but mainly in cities.



PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

Supports for people living in their own home tend to be provided by local authorities, the municipality. The most important types of services are listed in part 2 under the Act on Social Services. Professionals play a part as employees of municipalities. The level of support can vary from just some counselling up to 24 hours a day. Most people that have extensive support live in some kind of group home or “omsorgsbolig” but that is not required.

The extent and type of support is typically a decision of the municipality. Today many municipalities have split into a purchasing agency/office and providing units. The decision about extent of support will be done by the purchasing unit, most often based on an assessment made by a social worker or nurse. In most cases the person him/herself, and/or family members and/or a semi-guardian will be involved in the assessment, but the decision is up to the municipality. The decision can be appealed to the County Governor (State representative in the county, fylkesmann). The right to services is rationed. Thus an assessment will often be both about needs and a decision about which services you will be provided (thus the needs assessments are likely to be influenced by economic considerations).

The supports available to family carers are of several kinds. Some are special for family carers. The most important is economic support in the form of a care benefit. This is provided by the municipality and based on an assessment. About one out of three families of disabled children aged 11-13 years in 2006 received this benefit, with a mean annual benefit of 51 000 NOK (about 5,800 Euro) (Wendelborg 2007). This benefit is meant as a pay for the job done as a carer, but also as compensation for reducing the number of working hours. There is wide variation between municipalities regarding how this benefit is practiced.

In addition to this benefit, one have some supplementary benefits from the Social Security (State), related to either extra costs (called the Basic Benefit, grunnstønad) and extra care (called supplementary care benefit, hjelpestønad). Those benefits can in principle be for all people, and many disabled people receive grunnstønad. Hjelpestønad is mostly granted families with a disabled family member living with the family.

As for services, disabled people staying with their family, have access to many of the general services, such as day care, respite, leisure assistants, personal assistants, etc. These services are regulated by the Act on social services, and eligibility is based on the assessment procedures described above.

There is no very fixed and running system of quality control. At the national level two bodies do irregular quality controls (The Board of Health Supervision and the Auditor general of Norway). Both base most of their relevant activities on systems auditing, that is, checking whether procedures for local monitoring and decision mechanisms are in operation. In addition the county branch of the State (County Governor, fylkesmann) can do inspections. By and large, however, the quality monitoring system of municipalities is up to themselves, and is mainly linked to the renewal of service provision decisions (which is not primarily monitoring or quality assurance, but a decision about rationed services, thus municipal economy will also be a part of such decisions). Decisions on services from the municipality can be appealed to the County Governor (fylkesmann), which indirectly is a quality assurance mechanism.



4.1: PERSONAL ASSISTANCE SERVICES

The personal assistance scheme is one option under the Act of Social Services. The act is not very specific concerning eligibility, but the service is intended for people with severe impairments that needs practical support in everyday life, at home and outside the home. It is not restricted to certain types of impairments or diagnoses. In the early years it was restricted to people who are able to act as “supervisor” of assistants themselves, but the regulations today permits that this role can be supported by for instance parents or family members. Thus, earlier excluded groups such as people with intellectual disabilities can now have personal assistants (but so far the number is few). The service is intended to support an active way of life for people with severe impairments.

The service is a responsibility of municipalities and they pay for it. There do exist a temporary State contribution for the funding of services to new service users, in order to stimulate a transfer from traditional services to personal assistance. The contribution is 100,000 NOK the first year (about 12 thousand Euros). It is also possible to apply for 50,000 NOK for each of the three following years, but this is not automatically granted. The contribution is meant to cover costs for training of both the user and the assistant, and recruitment of assistants.

The service is provided by municipalities themselves or a cooperative of users (ULOBA, <http://www.uloba.no/templates/Page.aspx?id=223>). You apply for personal assistance to the municipality but ULOBA will help people with this as well.

According to municipal statistics by Statistics Norway 3714 received personal assistance in 2008 (calculated based on Statistics Norway’s Bank of Municipal Statistics). The number is increasing.

The level of support varies significantly across individuals, and there are no fixed limits. The individual is not allocated money or budgets, but a number of hours that the person him/herself has control over the use of – when, where and by whom.

In principle it is the municipality that decides how support and services are provided. It has however been discussed to strengthen peoples right to have services provided as personal assistance. There is a governmental proposal that people that have practical assistance of more than 20 hour each week according to the Act on Social Services, should have the right themselves to decide that it is organised as personal assistance. The final decision about this proposal has however been postponed several times and the enactment is uncertain.

If you move to another part of the country, you will most likely have to re-establish the service in the new municipality.



4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

Assistive equipment is provided under the Act of Social Security, and the service system is based on cooperation between municipal and state agencies called “assistive equipment centres” (hjelpemiddelsentraler (HMS)) that exist in all counties. The provision is rights based. In brief, the division of labour between the HMS and the municipalities are as follows: 1) The HMS provides the assistive equipment except for temporary needs (less than 6 months). Temporary needs are the responsibility of municipalities. 2) When people apply for assistive equipment, the normal procedure is through the local rehabilitation system. This could be a municipal occupational therapist, physiotherapist or GP. They provide documentation of needs and also assess the equipment’s potential for reducing functional limitations, for facilitation of participation in everyday life, and/or for increasing the person’s opportunities for finding or keeping a job. The application is sent to the HMS. The regulations on assistive equipment also apply to certain types adaptations at home or work.

People with impairments or functional limitations/activity restrictions lasting (or are likely to last) for two years or more have a right to assistive equipment. It applies to needs in the home, in everyday life, at work, in schools etc. The equipment is usually borrowed from HMS, and handed back if not in use.

Due to criticisms about a too bureaucratic application procedure, Norway has since 2006 adopted an arrangement called “brukerpass” (user pass). The arrangement was piloted in four counties from 2004. User pass implies that experienced users of assistive equipment can use a simplified procedure. The procedure requires that the person already have access to the type of equipment in question, but can use a simplified procedure with regard to replacement, repairs, etc. In practice it means that people do not need to contact the local rehabilitation system, but can go directly to the HMS and also to the supplier of the equipment. Evaluations show that people with user pass reduces contact with municipal services, and increases their contact with suppliers (Høyen and Tøssebro 2009). Time lags are consequently reduced.

There are about 150 thousand people with assistive equipment from HMS in Norway, most of them (65%) above the age of 67. In 2008 about 2500 people had a user pass (1.6% of the users of assistive equipment). According to the study of Høyen and Tøssebro (2009), 18% of people with a user pass were above the age of 67. The majority (65%) were between the ages of 36 and 67 (standard retirement age).

Costs for assistive technology are paid by Social Security. Users may have to use equipment that is already available at the HMS. The HMS negotiates prices and products that are made available to users, and there are restrictions on the allocation of products that are not on the list of price negotiated products. The lists are available on the national web-site: <http://www.nav.no/page?id=907>. There are financial limits to the support, but this is not definitive and varies across products. The basis is the price negotiated products, but exceptions are made due to needs. 200 persons had their applications for products outside the regular assortment accepted in 2007. In some cases, the user can also add his or her own resources to have a more expensive product. Support for an ordinary car is for instance a maximum of 144 thousand kroner (a very small car) but one can buy a more expensive car by adding the extra money out of one’s own pocket.

Since this is a national system, there are not restrictions that apply if people decide to move to another part of the country.



PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE

Three issues should be highlighted here:

- 1) The personal assistance scheme has been very welcome and evaluations tend to be very positive (Gulvik 2003; <http://www.ostforsk.no/rapport/pdf/032003.pdf>). ULOBA is organising the personal assistance for a number of people throughout the country. This is an organisation run by disabled people themselves. It has been very active promoting the use of personal assistance, and their contribution has been more user control over the service, not just at the individual but also the organisational level. One can read more about ULOBAs services in English at <http://www.uloba.no/templates/Page.aspx?id=223>
- 2) Norway has a fairly well established system for provision of assistive equipment. The introduction of user pass, in some countries (Denmark and Sweden) called “free choice”, gives the user opportunity to have more control in the process of acquiring, replacing, adjusting and repairing assistive equipment. It means more responsibility for the user, but you are not cut off from the regular system, but have the opportunity to choose a route to assistive equipment that is faster and with more self-determination.
- 3) We do not speak very much about deinstitutionalisation in Norway any more, since the main reforms now are nearly two decades ago. However, even though there are a number of shortcomings and worrying trends, the most important experience is clearly positive with regard to outcomes for the disabled people themselves. In my opinion, many European countries will have a lot to learn from the policies that were adopted in Norway and some other countries in the 1990s and that led to the replacement of the institutions.



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