



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

Country: Denmark

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PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

A number of countries such as Norway, Sweden, Finland, Latvia, Germany, Austria, Italy, Switzerland and England have centers or institutes for independent living, and groups of people with disability have formed cooperatives that provide services for independent living. The movement Independent Living has played a central role in the fight of disabled people. Denmark does not have anything similar, even though such services have existed as near as in Helsingborg for some decades. Development in Denmark has been quite different.

Alt the time of the first social reform in 1933 organisations of disabled people were already politically active, and in 1934 they formed the first umbrella organisation, now Danske Handicaporganisationer (DH), which from its inception was represented in all relevant parliamentary commissions. H.C. Seierup, the chairman of the commission that planned the second social reform in 1965-72 was also the chairman of DH.. In 1980 the Central Disability Council was formed.

Disabled people have of course fought for independent living in Denmark too, but this fight has taken place within the social reform system and has not created an Independent Living movement. It has resulted in legislation on technological aids, housing modifications and practical assistance and care in the home.

The system has developed so that today there are opportunities to choose another service deliverer instead of the municipality, or to have a friend or relative engaged by the municipality to give the help. User governed personal assistance (BPA) is the ultimate 24/7 solution, where the disabled person is the employer. Recently measures have been introduced so that other persons or companies may also act as employers so as to make this scheme possible for intellectually disabled people too.

There are however still problems for persons with significant physical disabilities . Even if these persons are known to the municipality when they are 12, 14, 16 years old, it often comes as a great surprise that they become 18 and have need of their own suitable housing. Often they have to stay in their parents' homes much longer than other young people do.

In 1998 the concept of an institution was abolished and many institutions were modified so that each resident got 2 rooms with a kitchen, became receivers of their own disability pension and paid for housing, meals and other services if they wanted them. This reform has had a large impact for elderly people in former nursing homes and for most intellectually disabled people in residences . There are however groups of intellectually disabled people and mentally ill people for whom this reform has not been as effective. People who cannot be cared for without use of force are not quite as easy to de-institutionalise.

In some respects developments since 1998 have gone in the wrong direction. New residences are often larger than the old ones. The rationale is often the increase of staff ratios, but it nevertheless counteracts the policy of integration.

The intention of the Law on Social Services (1998) was to divide the legal, bureaucratic and practical matters concerning housing form social service provision, . In reality, however, most accommodation facilities for disabled people are still organised as collective establishments, where services, meals and other daily routines are administered according to a central budget and a shared body of employees.



PART 2: LEGAL AND POLICY CONTEXT

People who need home help, home care, technological aids or modifications of their home in order to manage in daily life have the right to these kinds of services under the provisions of the Social Service Law (1998).

The Social Service Law makes provision for, among other things, municipalities, knowledge and counselling, user involvement, services for children, young people and adults, care, use of force, quality standards, compliance, financing and experimental schemes.

In 1998 the status of social institutions was changed so that “institutions” in the legal sense of the word no longer exist. The old buildings were changed so that each individual person got a little apartment with some possibility of doing their own cooking. The person was given the same status as other persons. He or she now gets a disability pension, and pays for the apartment. It is not mandatory to make use of any of the service provision. If meals are served, and the person wants to eat these, he or she has to pay separately for that. He or she is also served by the same home helpers and carers that serve other people in their own homes.

Naturally, some residences still have an air of total institution in the old sense of the word. But an independent way of living is the ideal even for people in residences.

An evaluation of the abolition of the concept of institution (Socialministeriet 2002) concludes that the law has had a positive influence on the situation of users in as much as larger institutions have been replaced with smaller ones, users now participate more in daily practical activities, they have more and more varied leisure activities, and they use their money differently. The abolition of the concept of institution has had least effect in residences where the users are most disabled, mentally ill or do not use verbal language.

Disabled People’s Organisations Denmark’s (DH) point of view is that the ideal of institutional abolition has not been sufficiently realised. There remain 1 institutions that offer a package of service and that think in an institutional way. Many persons do not have their own bathrooms, kitchens and their own entrances that can be locked, and many have apartments of less than 20 m².

As a point of departure, every person is considered independent and in control of his or her own life under the law.

The Service Law § 83 concerns the municipalities’ duty to care for people with reduced physical or psychical abilities. It applies regardless of consent.

A survey (Holmskov & Skov 2007) concludes that self determination is limited by two factors: orders from the authorities, for example that people living in residences must be weighed once a week, must eat soundly, etc. and lack of self esteem, self confidence and courage on the part of citizens.

A study of intellectually disabled peoples’ eating (Knigge 2005) describes different ways this can be negotiated so that open use of force is avoided.

In a number of service areas there is so-called free choice: if you are entitled to service it is possible to choose a private service supplier instead of a provider from the municipality.

If physical force is necessary, The Service Law § 124-129 must be respected.



Legal provisions are as follows: §125: 1. personal alarm systems, 2. special door openers (so that the disabled person cannot go out). §126: restraining a person if there is great risk of personal damage, or if it is necessary in connection with personal hygiene. § 127: restraining a person in his or her home. § 128 tying a person to a wheel chair or like. § 129: moving to special residence without consent. In most cases such actions must be absolutely necessary in order to avoid the person damaging himself or others.

If the staff in a residence use force, they must complete an official report in each time to the responsible authority. An evaluation of the practical use of force (Styrelsen for Social Service 2006) concludes that rules often are violated and many incidents are not registered according to official procedures. Consequently the legal rights of the citizen not are protected to the degree that was intended in the legislation.

Compulsory detention in a mental hospital is regulated in the Psychiatry Law (1989, 1998).

Guardianship may be established if a person is not able to manage their own affairs. It is always restricted to certain areas. It is available to people with mental impairment (e.g. dementia), a high degree of intellectual disability, or other forms of reduced health that makes the person unable to take care of his or her own affairs, and where assistance is needed. An example would be where an intellectually disabled person that inherits an amount of money and they require help to manage it.

According to the Law on Guardianship § 5 a disabled person can be dispossessed of his or her legal capacity if there is danger of that it will bring his or her fortune in danger.

Legally, there are no institutions. In reality there are all forms of residences from places where 10-15 persons are employed to care for one intellectually disabled person who has challenging behaviour, to residences where the residents only get a little support.

There are however still examples of residence-complexes where a number of smaller residences for intellectually disabled people form a so-called "village". The village Sølund near Silkeborg in Jutland is one of the largest, with 220 people living in a number of smaller residences and a staff of 550.

Some other initiatives in order to enhance self-determination are:

A network of intellectually disabled people (established by authorities) who can guide other intellectually disabled people as to whether or not to have children.

A survey (Skov & Henningsen 2001) involving 28 municipalities concludes that the attitudes of the authorities to intellectually disabled people having children varies greatly. Some municipalities remove the children while others give support to the parents.

Conferences have been held on the use of (mild) force in order to prevent intellectually disabled people from gaining too much weight, and also on the sexual abuse of persons with disabilities.

The new BPA (user controlled personal assistance) is discussed in the next section.

There have been a number of scandals concerning residences for intellectually disabled people. Examples include: in a residence in Nyborg a staff member videotaped staff members talking to residents in an impolite and brutal way, and in a residence in Copenhagen it was revealed that they had used force several times without reporting it.



In response, the Central Disability Council has established a think tank that will research these problems, propose new visions, and try to implement these (DCH Årsberetning 2008)

BPA (user governed personal assistance) started as an experiment in the municipality of Aarhus in 1976. In the 1980s it was incorporated into social service law; however it remained the case that more than half of the 300 users were from Aarhus. The conditions for entering this scheme were strict: people should have a higher than average level of activity outside the house and be young. The disability organisations have worked hard to make this scheme broader, and they succeeded with their endeavour in 2000.

The Law on BPA from 2000 makes provision similar to the Aarhus scheme but is relevant for a much broader group of users. It provides for personal helpers for up to 24 hours a day, 7 days a week. Therefore it gives people with a high degree of disability a real alternative to living in a residence. It also requires the person to take the role of employer in relation to the helpers. Intellectually disabled people have not been able to make use of this opportunity. There are however plans for a pilot project with BPA for intellectually disabled people.

It should be noted that BPA has not replaced ordinary home help and care for disabled people, but it is only a supplementary scheme that is used for persons needing the most assistance.

From 2009 persons using BPA have been able to choose for a private firm or a user-governed organisation to act as the employer. The Danish disability organisation (DH) has established a non-profit user-governed organisation; LOBPA, for this purpose. The intention is that LOBPA will not just administer the helpers for the individual member, but also engage in recruitment and education of helpers and negotiation of working agreements with trade unions, etc. The intention is to make arrangements so that the members get the most possible independence out of it, and the helpers at the same time have acceptable working conditions.

The Equal Opportunities Centre for Disabled Persons is in the process of establishing an independent think tank on the subject of housing for disabled people and deinstitutionalisation. Hopefully, this initiative will help to shed light on the reprehensible conditions concerning the implementation of policies supporting independent living for disabled people.



PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

In 2006 the number of places in residences for intellectually disabled people, people with physical disabilities etc. was 7.689, and the number of places in residences for people with mental impairments was 3.704 (numbers from Statistikbanken.dk).

It is estimated that there are 30-40.000 intellectually disabled persons in Denmark in the age group 18-65 years, that the majority of these live independently, as do the large majority of physically disabled people and persons with mental impairments.

The municipalities classify three broad categories of people as inhabitants in residences: persons with mental health conditions, persons with cognitive disabilities (here for example intellectually disabled and persons with autism), and persons with physical disabilities (including persons with acquired brain damage).

Numbers on persons with different types of impairments can be found in Bengtsson (2008). In the age group 16-64 years there are 66.000 persons with seriously reduced mobility in their legs, 63.000 in arms, 97.000 in hands, 20.000 with seriously reduced sight, 26.000 people with hearing impairments, and 26.000 with serious behavioural problems. The last mentioned group (which includes mental impairments) is the only of these groups with any significant number of persons in residences.

According to the law people can only be denied the right to live in the community if they are dangerous to themselves or to others. Intellectually disabled people who commit a crime and are convicted may be placed in a so-called secure residence instead of a jail. A psychiatric patient may be hospitalized against his or her will by a medical doctor. Persons who are cared for by the municipality and who cannot have the necessary care in their own home, or who cannot understand the consequences of their acts, or who expose themselves to great danger, can be moved to some sort of residence according to the Social Service Law § 129.

For many intellectually disabled people, people with autism etc, a residence is however the only option open to them, or if they have other opportunities it is the only sufficient solution for them. So they no doubt feel more or less forced to live there.

According to a recent study carried out by the National Federation of Social Educators (Socialpædagogerne 2009), many people with disabilities still live in accommodation that does not correspond with the general requirements of social housing. Of a total of approximately 17.000 people, more than 10.000 people live in accommodation that is too small. 6.400 people live in accommodation of less than 20 m². The study also claims that public investment in housing for disabled people has gone down by 65% in the period 2001-2007. There is, however, still considerable controversy regarding this figure.

On the other hand the disability survey (Bengtsson 2008) has shown that apartments between 40 m² and 120 m² have a greater percentage of inhabitants with disabilities than average, whereas apartments under 40 m² or over 120 m² have a smaller percentage of inhabitants with disabilities than average.

Another recent analysis carried out by The Equal Opportunities Centre for Disabled Persons (CLH 2008), gave evidence that many people with disabilities have to wait many months or even years before they are offered a place to live. The report demonstrated that the range of housing options in many cases is very limited as is choice of residence .



The report further substantiates the fact that even accommodation built according to the Law on Social Housing is often built in large clusters of 30 or more housing units and is often concentrated in smaller cities or suburbs away from the main cities of the municipalities

In 2007 the overall amount spent on permanent residences for persons with reduced physical or psychical functional ability or mental health conditions was € 1.123.354, of which mental health was 23%. Expenditure on temporary residences was € 426.003. The total amount spent on disability (excluding cash benefits) was 2.918.000.000 €. The average cost for a place in a residence was 256.000 €.

According to the Centre of Equal Opportunities (2008), a number of disability organisation representatives and municipal civil servants maintain that the development in some ways is moving away from community and independent living, as the municipalities have begun to build larger residential units again, e.g. with 30 or 50 apartments.

The reason given for establishing these larger units is not directly connected to the residents, but to do with it being more suitable to have a larger number of staff in the same place.

The disability organisations hold that the authorities still have an institutional mindset and build accordingly. Housing for disabled people is often placed in isolated locations. Disability organisations contend that housing should be where other people live, even if the residents are persons with an extensive need of care.

The minister responsible agreed, following an open consultation (17.04.2009), that Denmark could take inspiration from the Swedish model of units with a maximum of 6 apartments, which are individual homes in ordinary buildings. She presented however no concrete idea of the role the government might have in this. The responsibility for supply and regulation is with the municipalities.

A central problem in the current situation regarding housing for disabled people is that accommodation for disabled people is based on two alternative laws. The government has established some relatively advantageous financial premises on which to build accommodation facilities according to the Law on Social Housing. This law requires that every housing unit lives up to the national standards for all social housing, which among other things entails separate bedrooms, living rooms kitchens and bathrooms.

Alternatively, accommodation facilities can be built according to the Law on Social Services, which does not have the same requirements regarding size and facilities. A report carried out by The Equal Opportunities Centre for Disabled Persons (CLH 2008), argues that this constitutes a legal situation of unequal treatment.



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

Assistive equipment, housing modifications, practical help in the home, care in the home, extensive help (up to 24 hours 7 days a week), escorting for up to 15 hours a month, and support for transportation are available. There is also financial support that covers expenses due to disability.

All of this is provided by the municipality, which is the authority that is responsible for social support. This holds for services as well as for cash benefits such as disability pension. There is however some state refund: for disability pension it is 35 %, for social assistance and sick pay 50 % and for flexible working 65 %. Moreover there is an overall ceiling for the municipal costs for each single person, and the state covers expenses over that ceiling.

The support is granted to the person with disability. If the person with disability is granted a support that permits him or her to recruit the helper, he or she might engage a family member.

The municipality must offer support to a spouse, parent or other near relatives who care for a person with disability (Social Service Law § 84).

If the disabled person cannot live in the home without care that corresponds in the amount of time to a full-time job, and a relative or near friend who is in the labour market wants to care for the person, the municipality must engage this person for the care for up to 6 months, if there are no deciding considerations against this. (Social Service Law § 118).

The assessment is done by a social caseworker. In some municipalities a group of caseworkers is consulted for larger decisions; in others they consult with an executive.

In Denmark NGOs are not involved in assessing any social needs of any persons. Need assessment is a job for public social workers, and this is generally considered a guarantee of fair assessment.

According to the so-called principle of dialogue (§ 4 in The Legal Rights Law), the assessment decisions should not just be made, but should first be discussed with the disabled person.

The disabled person may make a complaint to the municipality, and if the decision is upheld he or she may appeal to a social appeal board in the region. If the case is important it may be heard by the National Social Appeals Board.



4.1: PERSONAL ASSISTANCE SERVICES

The municipality must offer care and practical help in the home to persons with temporarily or permanently reduced physical or psychical functional abilities or special social problems (Social Service Law § 83). They make a concrete, individual evaluation of the need. The right to assistance is not linked to any diagnoses or functional limitations.

The municipality must also offer help, care, support and training for development of capabilities for persons with temporarily or permanently reduced physical or psychical functional abilities or special social problems (Social Service Law § 85).

The person that is entitled to help according to § 83 may choose to select the person to give assistance. This person must then be approved by the municipality, which then draws up an employment contract with him or her (Social Service Law § 94).

There is also 15 hours escort per month for persons under 65 who cannot go out alone because of significant and durable reduced physical or psychical functional abilities (Social Service Law § 97); also contact persons for deaf-blind people (§ 98) and to persons with mental health conditions (§99). An evaluation (Sandø & Gruber 2006) concludes that this scheme fulfils a need but that more hours are needed by most of the users.

If a disabled person needs more than 20 hours help a week, he or she may chose to receive a cash sum as a contribution towards paid help that the disabled person himself or herself employs. In special cases the municipality can decide that the help must be given in kind, or that the amount should be paid to someone close to the person (Social Service Law § 95).

If the disabled person needs an exceptional amount of support, the municipality must give a contribution that covers the engagement of helpers for care, surveillance and escort. This is in instances where the disabled person is able to administer the scheme, engage the helpers and take the responsibility for the daily work organization (Social Service Law § 96).

Personal assistance for up to 20 hours a week is available in relation to work, through the Law on Compensation to Disabled People in Employment.

SSL § 83 (duty to care) and 95 (help must be given in kind, or money should be paid to someone close to the person) is only available in the home. SSL § 96 (financial contribution that covers the engagement of helpers for care, surveillance and escort)is available in the home, at work, in education, in training. § 85 (support and training for development of capabilities for persons with temporarily or permanently reduced physical or psychical functional abilities or special social problems) 97 (escort service) and 98 (contact persons for deaf-blind people) is available in the home or outside, but not for employment or education.

For SSL § 83 it is the municipality, for SSL §§ 95, 96 the person himself or herself. In 2009 a non-profit company, LOBPA, was formed to act as employer in instances when the disabled person does not want to do that himself or herself. www.lobpa.dk.

In 2007, 2152 persons under the age of 65 received more than 20 hours support a week. 1302 lived in residences, and 850 in their own homes. Those living in their own homes could choose the cash scheme, or could qualify for the § 96 scheme. Figures for each group are not known (Statistikbanken.dk).



The municipality pays for this support and there is no means testing or personal contribution. There is however a ceiling on the finances for help and support for each person in the form of a general state contribution of 50 % for expenses over 200.000 € for a person under 65 (briefly stated: the rules are in fact a little more complicated).

The exact rules are: in cases where expenses to help and support exceed 107.000 € a year the state refunds 25 % of the expenses over this amount, and if they exceed 201.000 € a year the state refunds 50 % of the expenses over this amount. (However a temporary provision was in place for the years 2007-2009). In 2009 : in cases where expenditure for help and support exceed 80.000 € per year the state refunds 25% of the expenses over this amount, and if they exceed 161.000 € pro year the state refunds 50 % of the expenses over this amount.

There are no financial limits to the amount of support someone can receive. Help according to Social Service Law § 96 may be up to 24 hours 7 day a week.

The municipality is responsible for all social support. Social support must meet the minimum standard as described in the law, but the municipality may provide a higher service level.

If the person moves to another municipality, the new municipality decides on the case, and the decision may be different as the new municipality may have a different service level. So if a person moves from Copenhagen to Elsinore or Malmoe he can not be sure of preserving his services.

If the disabled person temporarily moves to another municipality, the new municipality must continue to provide support, but the amount may be different according to the level of service in the municipality.

For SSL §§ 95, 96 the disabled person himself or herself controls the budgets. The municipality pays, and the person manages the money.

The municipal caseworker decides if a person has the legal capacity to manage the help schemes - that is, if the person has the intellectual capacity that is necessary.

In 2009 there is an intention to start a pilot project for assistance budgets for persons with intellectual disabilities, where another person, a private company or the newly established non profit company LOBPA will take the responsibility of employer.



4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

Persons with permanently reduced physical or psychological functional ability are eligible, if the equipment can remedy reduced functional ability to a substantial degree, can ease daily life in the home, or is necessary for maintaining employment.

Assistive equipment such as wheelchairs may be used in the home, at work and in education. Assistive equipment that is not personal, such as special work tools are awarded to the employer according to the Law on Compensation for Disabled People in Employment. For special education equipment goes to the school according to the Law on Special Education for adults.

The municipality is responsible for providing equipment and adaptation in home, at work and in education.

We have no statistics on number of users, but the expenses for assistive equipment were 320.000.000 € in 2007. (Statistikbanken.dk).

The municipality pays. There is however, as mentioned above, a general state contribution of 50 % for all municipal expenses for help and support over 200.000 € for a person under 65 (See the exact rules in 4.1).

There are no financial limits to the amount of support someone can receive.

The municipality is responsible for all social support. If the person moves to another municipality, the new municipality decides in the case, and the decision may be different.

If the disabled person temporarily moves to another municipality, it must continue support is continued but the amount may be different according to the level of service in the municipality.

There are no personal budgets for equipment or adaptations. The concept “personal budget” is in fact not at all used.

The municipality may decide that a certain supplier of assistive equipment must be used. If the equipment is personal (such as wheelchair and things worn on the body) the user may choose another supplier, but then gets only the amount that the municipal suppliers equipment costs (Social Service Law § 112).

There are special rules concerning hearing aids (probably because of the industry). A reimbursement of 728 € is given and people may choose supplier as they want.

The municipal caseworker decides if a person has the legal capacity to manage the help schemes, namely if the person has the intellectual capacity that is necessary.

The pilot project for people with intellectual disabilities, whereby third parties will take the role of employer, will include assistive technology and adaptations.

The Social Service Law contains support for assistive equipment (SSL § 112), consumer goods that are not part of most households (SSL § 113), cars (SSL § 114), house modifications (SSL § 116) and transportation (SSL § 117).

The Law on Compensation for Disabled People in Employment provides work place accommodations and work tools.



The State Education Support grants students with disabilities in advanced education special pedagogical support for , such as technological aids, educational materials, interpretation and practical support. The same arrangements exist in vocational education, where the schools and the State Education Support share the expenses.



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

Disabled peoples organisations were politically active from the 1920s, and influenced social reform in 1933. As a result of this, the umbrella organisation “Disabled Peoples Organisations Denmark” (DH) was formed 1934. Since then DH has been represented in all parliamentary commissions that have prepared legislation relevant to disabled people. The chairman of DH was also chairman of the social reform commission in 1965-72.

In 1980 the influence of disabled people’s organisations was made more permanent by the establishment of the Central Disability Council (DCH). DCH currently has 7 members from disability organisations and 7 members from state administration and municipal political leadership. DCH meets regularly and takes initiatives in all areas of disability policy. In 1993 DCH got a secretariat (Centre of Equal Opportunities, CLH) which now has 16 employees. CLH conducts practical research in areas that concern disability, conferences, campaigns etc.

Since 2007 disabled people have also been involved in municipal policy formation and development through the now mandatory municipal disability councils. It is too early to say what this will mean for municipal disability policy, but research on disability councils before they were mandatory indicates that they had an effect on the situation of disabled people (Research to be published)

The 32 member organisations of “Disabled Peoples Organisations Denmark” (Danske Handicaporganisationer, DH) all provide peer support to members, and some have also employed workers that support the members. Every person with a disability may join the relevant disability organisation.

The 36 member organisations of “Rare Disorders Denmark” (Sjældne Diagnoser), which are organisations of people with disabilities where there are less than 1000 persons with that condition in Denmark, also provide support to members.

As individuals, disabled people have been employers of publicly paid support since the first Aarhus scheme from 1976.

The BPA legislation from 2000 widened eligibility for previous scheme and an amendment in 2009 has opened up the possibility that groups of disabled people can form associations that function as employers and providers of support. To date LOBPA is the only example.

The quite new LOBPA is the only example. It was formed by a number of persons with need of support.

The chairman of “Disabled Peoples Organisations Denmark” (Danske Handicaporganisationer, DH) is a member of the first board. It is the intention that it will not only manage the individual helper schemes, but also engage in recruitment of helpers, education of helpers, (some disability organisations already train users of these schemes in managing assistants and making sure assistants do not take over), . It will be funded by municipal grants to users.



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