



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

**Country:** Finland

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## PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

The development of independent living among people with disabilities in Finland has developed from a collaboration between the state and civil society<sup>1</sup>. There are many specific acts (laws) that support independent living. At the policy level, the government organisation The Housing Finance and Development Centre of Finland (ARA) is an important agency for building and adapting housing for individual disabled people. Also ASPA Housing Services Foundation and ASPA Service Ltd. is a provider of customised housing and assisted living services for persons with disabilities, people recovering from mental health conditions, and other groups with special needs. Employment policy is also very important in the context of independent living.

The most significant development for independent living is the Act on Personal Assistance as a subjective right to disabled persons, which will come into effect on September 1. 2009. However in fact the process from institutional living to individual housing is very slow, and there is opposition from some interest groups. Some established institutions are worried that their dominant position in the field of institutional living for people with intellectual disability (ID) will be undermined. There are three reasons for this. Firstly, their ideology is based on the medical model of disability, whereby people with ID are considered as objects of care. The second reason is that institution staff fear losing their jobs. Thirdly, poor preparations have been made for residents to move out of institutions and into individual housing. There is furthermore a lack of supportive community services resulting in a trend toward mini-institutions.

There are examples of good practice: development projects for independent living, where is a good collaboration between disability organisations and authorities and even governmental organisations. However, disabled people face crucial problems with achieving independent living. This is because authorities control individual living initiatives and in practice service users do not have a powerful voice or influence. There is a struggle between financial politics and human and civil rights. There is a need for good practice to be strengthened.

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<sup>1</sup> This dichotomy is based on concepts developed by Gramsci (1971)



## PART 2: LEGAL AND POLICY CONTEXT

In Finnish disability policy, responsibility is spread over many administrative departments. As a minimum, independent living is understood as a matter of social policy, housing policy and employment policy. The purpose of Finnish social policy is to guarantee a meaningful everyday life to every citizen. In this sense all social policy legislation is an important part of independent living. However it is worth mentioning the following acts that are decisive in defining the conditions of the independent living of people with disabilities:

Act on Services and Assistance for the Disabled (380/1987), Act on Special Care for Mentally Handicapped Persons (519/1977), Act on Allowances to Improve Housing Conditions of Special Needs Groups (1281/2004), Non-Discrimination Act (50/2006).

These acts are based on an activation of services users' own capabilities (cf. Nussbaum 2006, 155-223).

The government organisation The Housing Finance and Development Centre of Finland ARA (ara.fi) supports new housing projects and restoration of contemporary housing stock, including tenements. According to the most recent statistical data (2007) special housing is subsidised in 784 new houses and this number has increased over 90% since 2004 (73 in 2004). (see [ARA statistics 2008 on Social Housing, table 2.](#))

Lately municipalities and special care districts have allocated financial support from ARA to build individual housing for people with intellectual disabilities, but this process is still under development. Another interesting provider of housing is [ASPA Service Ltd](#). This organisation provides customised housing and assisted living services for persons with disabilities, people recovering from mental health condition, and other special needs groups. Their locations are shown in the following map:

A brief observation of employment policy shows that efforts to employ disabled people mainly are focused on people with intellectual disabilities. (Hytti 2008; Hytti & Hartman 2008). However this situation is not necessarily permanent, because the forthcoming act on personal assistance as a subjective right to disabled persons hopefully will give more opportunities to other disability groups to get jobs. The act includes personal assistance at work places.





### **PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING**

In Finland institutional living is mostly concerned with persons with intellectual disabilities. Other disability groups usually use other housing services. Since the 1980s, the number of people with intellectual disabilities living in institutions has decreased. Today ca. 2,000 persons with ID are living in institutions and 8000 in community residences. This is only an estimate, because statistical data is not reliable. (Sotkanet, Vesala 2003, Niemelä & Brandt 2007, Peltto-Huikko et al. 2008). According to the latest study (Kumpulainen 2007) 24,000 i.e. 60% of all people with ID are estimated to live in their own homes or with their families.

3,000 people with severe disabilities (not people with ID) use housing services. This number of people has increased by about one thousand persons since year 2000. Housing services provide data on group homes rather than not institutional living (see <http://www.stakes.fi/FI/tilastot/aiheittain/Vammaisuus/index.htm>). Other statistical data on different disability groups in housing services is not available.

The process of moving from institutional living to individual housing is however very slow and some interest groups are against it, mostly because of structural reasons. Some old institutions are worried about maintaining their dominant position in the field of institutional living of people with ID. Their ideas are based on the medical model of disability, where people with ID are considered as an object of care. (Hintsala et al. 2008). The second reason is a threat of losing the jobs among institutions' staff. The third reason is a lack of preparation for moving out of institutions to individual housing. There is a lack of supportive services resulting in a trend towards mini-institutions. (Teittinen & Vesala 2009).

Several international and domestic research reports compare the costs of institutional living and individual housing. It is impossible to balance economics and improvements in people's living conditions. But this latter dimension is usually forgotten in the process of deinstitutionalisation. Arguments are usually based on economics, because big institutions are expensive to sustain. (e.g. Niemelä & Brandt 2007; Peltto-Huikko et al. 2008, Tøssebro 2006).



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

Most support services are arranged by welfare departments of municipalities. Their main concerns are developing strategies to implement housing services in practice, barrier-free living environments, services to all and individual services. At the strategic level individual solutions for various disability groups are emphasised. Public environments and building is based especially on the Act on Disability Services (380/1987) and the [National Building Code of Finland](#). Building houses for particular groups is part of municipalities' social policy. The newest housing stock is designed as accessible and has the potential for modification, if needed. Older housing stock is repaired and made accessible as possible. These well intentioned principles are not always put into practice; thus a number of disabled persons still live with their parents. One solution to this is the provision of caregivers as a part of housing services, in instances where individual municipal housing services are poorly organised. Caregivers act as a back up for disabled persons' housing when there are cuts in welfare services (Miettinen 2009). A problematic issue concerns everyday life commercial activities (such as shopping), because they are based on self-service, and in this situation a person with disability needs transportation and assistance.

Disabled people's individual services are based on a service plan that includes all their individual human needs and the support they need in their everyday life. Development of the personal service plan should be a dialogical process between a service user and authority, but usually authorities list the hopes of service users and calculate costs of wish lists. After that they decide themselves the about the content of the plan. There is a great deal of variation between the municipalities in how plans are drawn up and put into practice. Some of the services included in service plans, such as cleaning, are outsourced to commercial companies. NGOs' role in these kinds of services is quite small (Hintsala ym. 2004).

Recent research into independent living shows that disabled people consider their quality of life to be increasing, as is their interest in managing their own support. (see Eriksson 2008). Municipalities also provide financial support to family members when they are caregivers to disabled relatives. However some have criticised these measures as devolving too much responsibility to service users (Miettinen 2009).



#### 4.1: PERSONAL ASSISTANCE SERVICES

Assistentti-info is a nationwide network of personal assistance and information services, which produces educational materials. Its main focus is on developing personal assistance. [The Threshold Association](#) runs the network and its members are service providers, other disability organisations and foundations. Early developments in personal assistance began in the late 1980s, on a trial basis, but became more developed and enhanced within the independent living philosophy from 2005 (involving a three year project co-ordinated by the Threshold Association, The Finnish Neuromuscular Disorders Association, The Finnish MS Society and the Finnish Federation of the Visually Impaired).

Assistentti-info is now controlled by disabled people and provides a national co-ordinating and information function, as well as raising awareness about personal assistance and independent living. Advice and legal support can also be provided to personal assistance users (lawyers are employed).

The application process for gaining access to personal assistance services is provided for in Section 2 of the Disability Service Act, which provides for 'full or partial compensation for the costs incurred by him in having to employ a personal assistant and to purchase devices, machines and equipment needed in order to manage his daily affairs'. From September 2009, this will be a subjective right for all disabled people, including people with intellectual disability. This legislative change involves a budgetary law amendment to the law on services for disabled people. It would introduce rights to assistance for domestic, social, educational and employment purposes, including a right to 30 hours per month to support recreation and social interaction. The law also underlines the importance of involving the person in the assessment of need. The Bill was drafted in collaboration between the Minister of Health and Social Services and the Finnish Disability Forum.

The initial contact is for an assessment of need for personal assistance, with a social worker from the locality, to be initiated within a week of the enquiry. The Threshold Association claim that disabled people are often concerned that 'the social workers sometimes are not able to discern all their needs and the level of help they need as individuals are unique and coping systems vary, so they should listen more to the disabled person'<sup>2</sup>. Concerns had also been raised under the old system by the National Council on Disability, about constraints on the local assessment that often judged the need only for personal assistance at home (i.e. failing to meet the need for help outside the home and at work).

Eligibility for personal assistance is then determined by social service authorities, mostly based on applicants' functioning and medical diagnostics, and a service plan is drawn up. The allocation of personal assistance is usually given in terms of work tasks and work time. Severely disabled persons are able to get 24/7 personal assistance. People with disabilities may receive assistance at their homes and outside, for daily routines such as work, education, and to participate in hobbies and other activities (there are no restrictions on what assistance may be used for).

When the level of need is agreed, it is the responsibility of the disabled person to recruit and employ an appropriate person(s) to provide assistance. They have complete control over the recruitment, day-to-day employment, hours of work, etc (personal confidentiality is also a key principle in this arrangement). Alternatively, the person's guardian or carer may act as the employer of the personal assistant. Under the new law family members may not be employed as assistants except in exceptional circumstances. The wages for the assistant are provided by the municipality and may be paid either via the employer or directly to the personal assistant. Under the new law additional options would also be introduced.

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<sup>2</sup> <http://www.kynnys.fi/kynnys/english.html>



For example, the municipality could provide a voucher to purchase assistance or could provide assistance through its own services (whereby the disabled person would not need to be the direct employer).

Most services that are included in Disability Service Act have expanded since the beginning of the 1990s. The largest number of clients use transportation services. In 2006 personal assistance services were used by c4,500 disabled persons and other supportive services (e.g. interpretation) by c3,800. In 2008 c5,400 people were reported as using personal assistants.

There has been a 9% average annual increase in personal assistance usage and 3% in interpretation services in the last five years (see National Institute for Health and Welfare). Detailed statistical information and indicators (national, regional and local) are available from the NIHW's [Sotkanet](#). These register figures suggest an increase from 86.8 personal assistance users per 100,000 population in 2006, to 95.0 in 2007, and 102.1 in 2008 (not including interpreter services). A [detailed breakdown of these figures for each municipality](#) is also available. Information does not appear to be reported by gender.

There are limitations within the current system, such as a lack of resources, assistants and training to meet everyone's needs in some areas (there is unmet need for personal assistants) . The municipality pays only for the wages of the personal assistant and not for any additional costs for the user (low rates of pay have been identified as a problem also in recruitment). Some municipalities may be resistant to the use of personal assistants in place of traditional services. There is some concern amongst the municipalities about the potential expansion of demand for personal assistants and the challenges of costs and recruitment (e.g. the potential for rapid demand from older people).

An excellent [guide to the current system and new policy changes](#) is available from Assistentti-info (in Finnish). See also: <http://www.kynnys.fi/content/view/617/607/>



## 4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

Assistive equipment and adaptations are included as a public service for people with disabilities. According to the Ministry of Social Affairs and Health '...assistive devices are available from health centres or by referral from the assistive device units of health care districts. Assistive device services include instruction on use, renewal and maintenance. The services are free of charge. Assistive devices for use to help with social life and recreation are also available as a disability service from social welfare departments.' Also '...people with severe disabilities are reimbursed for renovations made to their home and for devices installed in the home, as well as for the costs of acquiring devices and equipment.'

The application process for getting assistive equipment and adaptations is the same as for personal assistance services (see point 4.1) It is included in Section 2 of the Disability Service Act and assessment is carried out by social service authorities. Their evaluations are mostly based on applicants' functioning. The procedure involves an applicant filling out an application form by himself/herself or with a social worker. Usually a medical statement of functional limitations is needed, with applicant's own account of his/her difficulties in everyday life.

In 2008, 8,588 were reported as using housing conversion and equipment services under the Act (an increase from 8,599 in 2007, and 8,125 in 2006). Detailed statistical information and indicators (national, regional and local) are available from the NIHW's Sotkanet. These figures show the increase from 154.0 users per 100,000 population in 2006, to 162.2 in 2007, and 161.2 in 2008. A [detailed breakdown of these figures for each municipality](#) is also available. Information does not appear to be reported by gender.





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

As mentioned above, (section 4.1) Assistentti-info is a network that includes about 15-20 disability organisations, which collaborate with other partners. There are divisions for education, research and development, work counselling and legal assistance. The practical achievement of the network has been to establish centres for personal assistance. The Threshold administers this project. Values of the centres are self-determination, independent living and human rights, equality, expertise and reliability and validity of services. The idea is to establish district offices and there are already five of these run by the Threshold which provide essential knowledge of the issues.

Important for this is the collaboration of municipal authorities, local political decision makers and civil society associations. The funding of the centres comes partly from municipalities and partly from the national Slot Machine . (see [www.kynnys.fi](http://www.kynnys.fi) , <http://www.kynnys.fi/assistentti.html> , [http://www.kynnys.fi/images/stories/assistentti.info/web\\_kohti\\_yhdenmukaista\\_kytnt.pdf](http://www.kynnys.fi/images/stories/assistentti.info/web_kohti_yhdenmukaista_kytnt.pdf))

The Threshold Association was established in 1973 by a group of disabled students, and promotes enabling alternatives based on fundamental human rights. It has offices in six locations (in the capital and five regional cities).



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