

ANNEX VIII: FINLAND

BACKGROUND

(1) What definitions of Intellectual Disability are typically used in your Member State? Is there an 'official' definition?

International Statistical Classification of Diseases and Related Health Problems (ICD-10), World Health Organization 1992 is used in Finland to define intellectual disability.

(2) What is the historical context in which services have developed in your Member State?

The Ministry of Social Affairs and Health leads the development of social welfare and health care legislation and services. The Ministry is in charge of the planning, guidance and monitoring of services. The municipalities are responsible for providing the necessary social welfare and health care services. The Social Insurance Institution is in charge of the medical rehabilitation of severely disabled persons, vocational education for disabled persons, and their income security during periods of rehabilitation. Legislation obliges the municipalities to provide the necessary social and health services for their inhabitants. Municipalities can provide these services by themselves, in co-operation with other municipalities or by purchasing them. Five Provincial State Offices guide and monitor the operations regionally.

There is a National Council on Disability linked to the Ministry of Social Affairs and Health, consisting of eighteen members. It is a co-operative body between the relevant authorities and disability organisations. Good decisions pertaining to disability policy can be brought about only by combining the expertise of people with disabilities and that of the public administration. There are about 220 municipal councils on disability, in which the different sectors of administration and NGOs co-operate at the local level.

The Advisory Board for Rehabilitation is a co-operative body of the Ministry. The Advisory Board has eighteen members representing the authorities and institutions in the field of rehabilitation, disability organisations, municipal central organisations and labour market organisations. The task of the Advisory Board is to promote the drawing up of development plans and objectives for rehabilitation and to monitor the implementation of legislation. In addition, each hospital district has a regional co-operation commission for client service within rehabilitation. There are corresponding liaison groups for the local authorities in about 280 municipalities.

Starting points for Finland's disability policy

In 1993 the United Nations adopted Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. On the basis of these Finland set out its own disability policy programme in 1995. Its aim is to promote the independent living, equal opportunities and participation in society of persons with disabilities. These goals can be achieved by increasing the independent initiative and decision-making power of persons with disabilities and by eliminating physical, attitudinal and communication related barriers to access. In the context of the reform of the constitutional acts, the Constitution Act of Finland was amended in 1995 with a provision on the equal treatment for persons with disabilities, according to which no one shall be assigned a different status on the basis of their health or disability. It is required that the state and municipalities work actively for implementing the rights of persons with disabilities. There are separate provisions on the obligations of municipalities elsewhere in the law.

Disability organisations

Disability organisations have originated from charity work for persons with disabilities. These organisations have developed into interest organisations that draw attention to disabled persons' needs and advocate and promote their rights in society. The role and influence of disability

organisations in society is significant. They have direct contacts with Parliament and influence actively political decision-makers. They act together and separately taking initiatives and issuing opinions at different levels of administration. Their representatives take part in working groups and committees of public administration. Disability organisations increase the awareness of their members of issues related to their impairments and to their societal rights. They strengthen the identity of disabled persons and their facilities to influence their own living conditions. Besides increasing the awareness of their own members, these organisations also work for increasing the information and awareness of the whole population about disability issues.

Most disabled persons are organised according to their type of disability. Disability organisations are in general rather large; they have paid employees and local associations with large numbers of members, who also do voluntary work. In addition, there are small nation-wide voluntary organisations. There are altogether about 80 disability organisations in Finland. These have an umbrella body called the Disability Forum, which is at present intensifying its liaison work. Disability organisations also provide and develop special services needed by disabled persons, such as rehabilitation, educational and housing services. This action presupposes interaction and co-operation with the authorities. State and municipal authorities purchase services from disability organisations to supplement their own service provision. Disability organisations obtain part of their funding through their own campaigns and membership fees. A Finnish peculiarity is the Slot Machine Association, which has a monopoly to run slot gaming machines, and provides disability organisations with sizeable financial support from its revenue.

Service Foundation for People with Intellectual Disability was formed in 1992 by The Finnish Association of Societies for Persons with Mental Handicap. The purpose of the foundation is to promote and support people with intellectual disability and their families by its services. The Service Foundation seeks and develops new practises in order to ease the everyday life and improve the quality of living for people with intellectual disability and their families. The Service Foundation operates nation-wide and creates models of human, functional and good-quality services.

The Finnish Association on Mental Retardation (FAMR) is a national central organisation and a co-operative forum for organisations and persons working for the better quality of life for people with intellectual disability as well as others in need of support in learning, understanding, and communicating. The experience gained through the FAMR's research and development projects gives guidelines and direction for the future: focusing on humanity and equality where everybody is provided with the services they need within their own living environment. Through the Association's activities, good practices are identified to serve persons with learning disabilities. The FAMR wants society to offer each and every one of its members the services they need in a flexible manner. In that way, being different is not a factor which separates people but a factor which contributes to the welfare of everybody.

Services for life

A normal living environment with daily routines is the basis of equality and a good life for a person with intellectual disability. A good start in the life of a disabled child is promoted by early rehabilitation and day care and also by providing sufficient and flexible rehabilitation and support services to the family from the very beginning. Towards the end of life, an elderly person with intellectual disability is entitled to being treated as any other person of the same age.

According to the FAMR, equality will be a reality only when those services used by others can also be used by the intellectually disabled and other persons in need of support. The services available need to be based on individual needs and fitted to each person's needs. Day care, training and education, work, and culture must be available for everybody. The Association wants businesses, in their service and product development, also to take into consideration humanity, exceptional people, and equality.

Development challenges

The focus of disability policy is being shifted from services and rehabilitation to removing obstacles to the equal participation of disabled persons. Society as a whole is responsible for taking into account the needs of persons with disabilities. The improved accessibility of housing and the living environment, transport, communication and information would enable their empowerment and participation. Resources are focused so as to encourage persons with disabilities to be active and take initiatives for themselves. The different disability groups are treated equally. The goal of the near future is to maintain and promote the functional and working capacity of persons with disabilities, with special emphasis on supporting the independent living of severely disabled persons.

(3) Are there specific legal rights afforded to people with intellectual disability?

Education, disability specific service provision, etc.

Situations where rights may be revoked on the basis of incapacity?

Disability services and care of people with intellectual disability

The aim of the Act on Services and Assistance for the Disabled is to promote the independent living and equal opportunities for persons with disabilities. The Act is, however, subsidiary, and the necessary services and supportive measures shall be provided by municipalities primarily on the basis of general legislation. Disability is defined in relation to how a person copes with everyday situations. Functional capacity cannot therefore be assessed only medically.

About five per cent (250,000 people) of the Finns have an impairment or disability involving considerable handicap. Less than one per cent of the population are seriously disabled and need various services and support measures in order to attain a position equal to other citizens.

Therefore municipalities are by law obliged to provide seriously disabled people with such services and financial support necessary for independent living. This responsibility applies to transport services, service housing and interpreter services. Furthermore, the municipality has to compensate for the costs of alterations and repairs to flats and of obtaining equipment and devices needed in the home. If a disabled client considers that the municipality does not provide the statutory services and support, he or she may apply a decision of the social welfare board to the Provincial Administrative Court and further to the Supreme Administrative Court.

Special care of people with intellectual disability

The special care of people with intellectual disability is based on separate legislation, which is secondary in nature. Finland is divided into sixteen districts for special care, which must organise the special care that the local authorities are obliged to provide. In addition, there is a specific district for the Swedish-speaking population, consisting of Swedish-speaking and bilingual municipalities. The districts provide the services needed by people with intellectual disability. Municipalities may also arrange special care or buy services from another municipality or private service producers. They mainly concern housing services, day activities and leisure activities, family care and residential care. The special care districts also complement with their special expertise the services provided by municipalities.

Co-operation of authorities

Since the rehabilitation system is complicated there is separate legislation on co-operation concerning rehabilitation services. This obliges social welfare and health care, labour and educational authorities and the Social Insurance Institution to co-operate in co-ordinating the rehabilitation measures and services. Furthermore, these authorities are obliged to co-operate with other relevant service systems.

The legislation also obliges municipalities to see to it that there is a working group on co-operation in respect of rehabilitation services in the municipality. In addition to the general promotion of this co-operation, the working group can also handle such problematic cases in which no solution has been found otherwise. It is important that the client is involved when his or her case is dealt with in the working group.

Services for children and families

The birth of a disabled child involves much stress for most families. Social welfare and health care professionals help parents of disabled children by giving them support and information on disability at an early stage, preferably starting at the maternity hospital. Child health clinics monitor and support the development of children, and an effort is made to detect any developmental retardation as early as possible. If needed, children are referred to continued examinations and to specialised services within social welfare and health care. The medical, educational and social rehabilitation of children with disabilities and their families is started immediately after the impairment, illness or retardation in development has been detected. Parents are entitled to municipal day care at a day care centre or within family day care for their children under school age. The best possible day care alternative is tried to be found for each disabled child: family care is suitable for some children, day care centre for others. In day care disabled children are primarily integrated into the same group with other children, but care can also be provided in special groups. Parents can also receive financial support if they choose private care. If parents want to take care of their children under 3 at home, they are paid home care allowance. On certain conditions home care allowance is also payable for children older than that. Parents pay a fee for day care determined on the basis of the family's size and income. Special services, such as personal assistance in day care, and rehabilitation and aids are free of charge.

In school the learning and development of children with disabilities, as well as their parents are supported by a team consisting of the school health nurse, special education teacher, school social worker and school psychologist, and if necessary, a doctor and speech therapist. Health care is responsible for medical rehabilitation. Seriously disabled children are entitled to rehabilitation organised by the Social Insurance Institution. Adaptation training for children with disabilities and their families is arranged by municipalities, the Social Insurance Institution and disability organisations.

Parents of children with disabilities can apply for various financial benefits paid by the Social Insurance Institution. The most important of these are the care allowance and special care allowance for children. Care allowance is paid to parents if the child's care involves special burden in terms of care or financially at least for six months. Special care allowance compensates for the loss of earnings during the time parents are caring for the child or staying with the child at a hospital or out-patient clinic.

A variety of services is provided by different service providers to children with disabilities and their families. Parents are not always aware of which services and benefits they are entitled to. Therefore the authorities draw up with the parents a service plan including all the services and benefits needed by the child. A contact person is appointed to act as a link between the family and different authorities.

Instruction and education of children

Children and young people with disabilities are entitled to participate in all education on an equal footing with their peers. They often attend comprehensive school along with their peers, receiving in addition, if necessary, special or remedial instruction. Furthermore, some are instructed in a special class in an ordinary school, while others attend a special school, for instance where sign language is used. Sign language has in Finland status as a language of instruction. Starting from 1999 it can be taught as the mother tongue in the comprehensive school, upper secondary schools and vocational education institutions.

The compulsory education of children with disabilities lasts a year longer than that of other children, 11 years. The municipality is responsible for providing children covered by extended compulsory education pre-school instruction for one or two years. This applies to children with intellectual disability, hearing loss and visual impairment, children with serious mobility impairment and children suffering from a serious illness. These children are entitled to attend municipal comprehensive school or to receive instruction in some other way.

Children with disabilities are entitled to free interpreter services and assistance if it is necessary for participating in instruction, to other instruction services and pastoral care of pupils, aids and support services related to special education, such as rehabilitation in connection with instruction. Pupils of vocational institutions or upper secondary schools can also receive personal assistance. School transport of children with serious disability is free of charge.

Physical access and access to information

In recent years the aim in the planning of buildings and traffic arrangements has been to attain a built environment where all people can cope independently. Increasingly architects, traffic planners and developers understand that houses without lifts, small cars and inaccessible trains and inaccessible services belong to the past. Modern technology provides good opportunities for this. But in order to ensure progress disability organisations and authorities need to be constantly vigilant, since Finnish society is not yet accessible to all people.

Built environment

Stairs or lifts which are too small or lacking altogether, cramped bathrooms, high thresholds and narrow doors restrict the accessibility of the built environment. Buildings need to be adapted for children, older persons and disabled persons. The shaping of the built environment is guided by legislation and standards. Reformed construction regulations concern new buildings and alterations and renovations. There are several stages from a good plan to the completed new building, and ignorance and fear of extra costs often result in poor and unworkable solutions. Understanding of these issues is continuously promoted in the education of construction professionals.

Public transport

The goal of traffic policy is public transport accessible to all. The accessibility of vehicles is not guided by society through legislation. The Ministry of Transport and Communications aims to promote the accessibility of transport through research, information and co-operation of various actors.

Access to information

It is particularly important to remove obstacles to communication for persons suffering from sensory defects. Finnish disability organisations have been pioneers in developing accessible models of information. The public administration has also contributed to introducing and financing new methods.

Deaf and hearing impaired people are able to follow what happens in the world daily through teletext and TV news in sign language. It is also possible to receive personal interpreter service. The use of information technology has increased visually impaired people's access to information: e.g. the largest Finnish newspaper is available on the Internet, where it can be read by the appropriate technology. A library for the visually impaired provides both fiction and study material for visually impaired people. Disability organisations co-operate in publishing books in plain language. A regular newspaper in plain language contributes to satisfying the need for topical information.

(4) What is the estimated prevalence figure for intellectual disability in your Member State? Both in terms of an estimated 1-3% of the population who have an IQ is less than 70, and in terms of known service users.
Is there any published material on prevalence studies?

Available information regarding population and people with Intellectual Disability in Finland:

Temporal changes in incidence and prevalence of intellectual disability between two birth cohorts in northern Finland. *Am J Ment Retard.* 2003 Jan;108(1):19-31. Heikura U, Taanila A, Olsen P, Hartikainen AL, Von Wendt L, Jarvelin MR

Two separate cohorts of children born in 1966 (n = 11,965) and 1985-1986 (n = 9,432) in Northern Finland were followed to determine temporal changes in the incidence and prevalence of subcategories of intellectual disability within the same geographic area. The children were followed up to the age of 11.5 years. Similar study design, data ascertainment methods, and definition of intellectual disability were used. There was no change in the total incidence (12.62/1,000 in each) or in total prevalence (11.03/1,000 vs. 11.23/1,000) of intellectual disability. However, in the subcategories of intellectual disability, there was a shift from severe and moderate towards mild; whereas profound intellectual disability remained at the same level.

Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *J Intellect Disabil Res.* 2003 Feb;47(Pt 2):108-12. Arvio M, Sillanpaa M. The number of people with severe and profound intellectual disability was 461 in a population of 341,227 giving a prevalence of 0.13%.

The number of people with intellectual disabilities registered in the Customer Registers of Social Insurance institution of Finland was 28 682 (total population 5 200 000) 31.12.2002.

(5) What databases/sources are available in your Member State that might provide information on prevalence? Medical or social benefits; disability databases etc.

The National Research and Development Centre for Welfare and Health (STAKES) produces information and know-how in the field of welfare and health and forwards them to decision-makers and other actors in the field. As a centre of expertise overseen by the Ministry of Social Affairs and Health, STAKES bases its functions on research, development and information resources.

<http://www.stakes.fi/english/index.html>

Facts about services for people with intellectual disability are available in

<http://www.stakes.info/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Hilmo/teemanetti> and <http://www.stakes.fi/sotka/>

Statistics Finland (Tilastokeskus) operates administratively under the Ministry of Finance, but is fully and independently responsible for its activities, services and statistics. Statistics Finland combines collected data with its own expertise to produce statistics and information services for the needs of society, promotes the use of statistics and develops national official statistics.

http://www.stat.fi/index_en.html

The Population Register Centre (Väestörekisterikeskus) develops and controls the registration, maintenance and delivery of population information together with the local register offices.

http://www.vaestorekisterikeskus.fi/vrk/home.nsf/pages/index_eng

The Social Insurance Institution on Finland (KELA) provides basic security for all persons resident in Finland, covering the different stages of their lives. KELA operates under the supervision of Parliament.

<http://www.kela.fi/in/internet/english.nsf/>

SERVICE PROVISION

(6) What is the criterion for eligibility for intellectual disability services?

The aim of disability policy is to safeguard the economic and social situation of all municipal residents with disabilities regardless of their need for particular services. A focus of this work is to eradicate obstacles to the participation of disabled people, provide services and rehabilitation.

Financing of services

The Finnish disability policy is based on the Nordic welfare model. The aim is to secure all municipal inhabitants the services they need, irrespective of their financial or social status. The model used is mainly revenue-financed public services, complemented by private services and NGO activities. The municipalities receive state subsidies for organising statutory health care and social services. The Finnish Slot Machine Association finances part of the activities of NGOs and certain foundations. There are about 70 national disability organisations in Finland. They also provide services that are purchased by municipalities.

- (7) What type of service provision is currently offered to adults with intellectual disability?
Educational, day service, residential, etc

The principle of the organisation of services is the primacy of universal services. However, in their everyday life disabled people need special services for housing, aids, transport and interpretation.

A personal service plan is drawn up for each disabled person to clarify the services and support he or she requires. Officials of the municipality together with the client and his or her carer or relatives prepare the plan. The service plan is designed to improve the clients' autonomy and their possibilities to influence their situation. A counsellor, who is tasked to accommodate the various services together and call meetings of other relevant officials, checks the plan within specified timeframes.

Disability services and care of people with intellectual disability

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Transport services

The municipality provides seriously disabled persons with transport services needed for being able to work, study, participate in society, and for recreation. A person is considered seriously disabled if he or she has special difficulty in mobility and cannot therefore use public transport. If needed, these persons are provided with an escort. Besides journeys to and from work and places of study, they can make up to 18 journeys a month in their own municipality or in its vicinity. Transport is provided mainly by taxi, though joint transport and service lines are also becoming more general. The client pays the same price for this transport as for public transport.

Interpreter services

The municipality provides free interpreter service for the deaf-blind and for persons with serious hearing impairment or severe speech impairment. Interpreter services are provided in sign language or by other forms of communication using new technology. The deaf-blind are entitled to 240 hours and others to 120 hours of interpretation a year. Interpreters are mainly employed on a freelance basis. Various ways of organising interpreter exchange regionally have also been developed. Interpreter services vary from one municipality to another.

Service housing

Service housing covers, besides the flat, services related to housing that enable even seriously disabled persons to live normal lives independently. Services are provided to seriously disabled persons who owing to their impairment or illness need regular assistance in everyday life for a certain period during a day. Institutional services guarantee continuous care and attendance on 24-hour basis. Service housing can be arranged in the client's own home by means of home and nursing services and personal assistance. Service housing is also arranged in service flats and group homes designed for the purpose. The need for services varies, and therefore they are

planned together with the disabled person concerned. A disabled person pays rent and other costs in the same way as other people do, though the additional assistance needed because of disability is free.

Home alterations and equipment and devices

A seriously disabled person must be reimbursed for the costs of alterations to the flat and obtaining equipment and devices needed in it. The alterations must be necessary for the person's independent living, owing to his or her disability or illness. Usual alterations comprise changes in the bathroom and kitchen, making doors broader, removing thresholds and building ramps. The costs of planning the alterations and removing barriers in the immediate environment are also covered.

The equipment and devices needed in the home include fixed hoists, safety alarm devices, lifts, textphones, fixed high technology equipment and induction loops. If a person needs household appliances, the municipality pays half of the costs or delivers an appliance free of charge for the disposal of the person. The requirement for compensation is that the piece of equipment is needed owing to the person's handicap.

Personal assistance

The municipality may at its discretion reimburse a disabled person for the costs of employing a personal assistant. The system of personal assistance has been created to enable the independent living of seriously disabled persons. It contributes to reducing dependence on the family and avoiding placement in an institution. A personal assistant is needed to assist a disabled person in everyday situations at home and in activities and hobbies outside home. The aim is that persons with disabilities should be able cope independently in working life and studies. Disabled children are provided with an assistant at school and in day care, if needed.

A personal assistant is employed by the disabled person. Therefore it is required that the disabled person or his or her guardian is able to function as an employer and fulfil the obligations of an employer. The municipality may give guidance to disabled employers. The aim of the system is to reduce the level of the disabled person's dependency, and therefore it is recommendable that a close relative should not be employed as personal assistant, though this may be justified in some cases.

Adaptation training and rehabilitation counselling

Adaptation training helps a disabled person to lead a full life despite his or her impairment. Adaptation training is usually arranged in the form of residential courses. There is favourable experience from groups that convene at regular intervals. New stimuli to adaptation training have been given by peer support activities where a disabled person guides and supports other disabled persons. Adaptation training has very definite goals, such as learning how to live independently. Training is also arranged for the families of children with disabilities.

Through rehabilitation counselling persons with disabilities are referred for services. A rehabilitation counsellor draws up an individual service and rehabilitation plan together with the disabled client and authorities. Rehabilitation counsellors work mainly in health care and in disability organisations. Municipal social work can also be regarded as rehabilitation counselling in identifying a person's service needs and referral for services.

Teaching Materials Centre for Special Education and Rehabilitation

With the help of various materials, the goal of the Teaching Materials Centre is to support the life of the intellectually disabled towards increasing independence and competence. The Centre plans and produces modern high-quality materials for educational and rehabilitative purposes to be used by exceptional learners.

The product range of the Teaching Materials Centre includes books, games, computer

programmes, and videos. The Centre also adapts foreign rehabilitative and educational methods to Finnish circumstances. In collaboration with the field personnel and other specialist professionals, the Teaching Materials Centre actively participates in developing special education and rehabilitation.

Tikoteekki Assists in Problems with Communicating

The Communication and Technology Centre Tikoteekki promotes the best possible communication for people with complex communication needs. Most of the people who have difficulties in either speech reception or expression can benefit from the usage of augmentative and alternative communication methods (AAC methods), communication aids and supportive computer programs. Tikoteekki gathers and distributes knowledge concerning AAC methods and the newest technical solutions in communication devices. Tikoteekki also offers training to the teaching, therapy and care professionals. Additionally, Tikoteekki provides assessment of communicative skills to persons with speech and language impairment. Furthermore, the Centre offers computer usage assessment, which aims to find the best means for the individual to use computer as a tool. The assessments are carried out in a co-operation with the client's daily contact persons. Tikoteekki Centre in FAMR co-ordinates also a national network of eleven regional Tikoteekki centres in various parts of Finland.

By means of research and projects the Centre develops client based activity standards in cooperation with professionals, hospitals and universities. Furthermore Tikoteekki participates to the national and international collaboration through projects, networks and conferences.

Plain Language Centre Promotes Plain Language Communication and Culture

The Plain Language Centre publishes a biweekly plain language newspaper, Selkouutiset in Finnish and LL-Bladet in Swedish, with articles on current events and news. In collaboration with the Ministry of Education, it promotes the publication of literature in plain language. In addition, the Centre generates ideas and implements plain language applications, provides services, and organises training and education.

The Plain Language Centre assists other organisations in realising plain language communication. It has prepared, among others, the Finnish Constitution and EU material for dissemination in plain language. And, the goal of the Plain Language Centre is to be a channel for plain language collaboration and information dissemination.

Vocational rehabilitation

The purpose of vocational rehabilitation is to improve or maintain the client's working capacity and opportunities for earning a living. Vocational rehabilitation may comprise vocational guidance, examination of the need for rehabilitation, work and training try-outs, work training, vocational and other education, employment counselling and job placement, support for running a business, aids needed at work or in studies, and financial support for rearranging working conditions. Vocational rehabilitation is organised by the labour authorities, the Social Insurance Institution, employment accident and motor insurance scheme, employment pension insurance scheme and vocational education institutions. The amount of the income security during rehabilitation and the conditions for entitlement vary.

Municipalities organise traditional sheltered work for persons who, owing to their disability, illness or impairment, do not have access to employment on the open labour market. There are about 3,000 persons in sheltered employment. Sheltered workshops maintained by municipalities, joint municipal boards and private agencies number about 130, and provide training and working skills.

Service plan

In order to find out which services and supportive measures a disabled person needs and to co-ordinate these, the authorities draw up an individual service plan together with the disabled

person and his or her custodian or family members. The starting point is the client's service needs. The purpose of the service plan is to improve the client's right of self-determination and leverage. The service plan is a co-operation instrument based on the client's involvement and a close co-operation between different authorities. The plan is checked at regular intervals, and a person is appointed with the responsibility for co-ordinating the services and liaising with the relevant authorities.

Special care of people with intellectual disability

The special care of people with intellectual disability is based on separate legislation, which is secondary in nature. Seventeen districts for special care provide the services needed by people with intellectual disability together with municipalities and private service producers. The special care districts also complement with their special expertise the services provided by municipalities. The special care of people with intellectual disability has undergone much change in the 1990's. In practice the responsibility for providing services has been shifted from the special care districts to municipalities. The role of institutions has been gradually reduced and the focus shifted to services arranged by municipalities in the community where the person with intellectual disability lives. There are great differences in different parts of the country in how services are provided. The number of clients also varies greatly from one municipality

In Finland, about 22,000 people with intellectual disability need special services to complement the municipal social welfare and health care services. About 14% of them are in institutional care, about 6% in family care, about 20% are provided with housing services, and about 20% live independently. About 40% of them live with their families.

(8) What sources of income are available for people with intellectual disability?
Benefits – provide some index of national minimum wage as a reference point

Entitlement to benefits

Care allowance for a sick child

The home care of a sick child is supported by paying the family a care allowance if the child's illness and its care involve special financial or other burden on the family. An increased care allowance is paid when the burden entailed by the care and rehabilitation of the child is considerable, and a special care allowance is paid when that burden is extremely big. Such children include those suffering from serious sensory defects (deaf-blind), people with severe intellectual disability and children with multiple handicaps. In 1998 the allowance was paid for 45,000 children.

Rehabilitation allowance

Those participating in rehabilitation are paid a rehabilitation allowance if they are not able to work during that time. It is in general of the same size as daily sickness allowance. The aim of rehabilitation is to promote the access or re-entry to working life or remaining in it. All people aged between 16 and 18 are provided an opportunity for vocational rehabilitation. Young people are paid, instead of disability pension, a rehabilitation allowance on the basis of an individual study and rehabilitation programme. The purpose is to support their studies and access to employment.

Disability allowance

Disability allowance supports disabled persons aged between 16 and 64 to cope with everyday life and to take part in working life and studies if they do not receive a full pension. The economic situation of the applicant does not influence the entitlement to disability allowance. Disability allowance is payable to persons whose functional capacity has been reduced owing to illness or impairment for at least one year. The lowest allowance is payable to persons for whom the illness or impairment entails essential disadvantage and continuous extra costs. Increased disability allowance is payable to persons whose illness or impairment entails considerable disadvantage or who need regular assistance, guidance or monitoring in their personal routines,

household work and when shopping etc. or for whom the impairment involves considerable special costs. A special disability allowance is paid to persons who are seriously disabled and who need every day assistance, regular guidance or monitoring in many of their everyday routines or for whom the illness or impairment entails big special costs. At the end of 1998, disability allowance was received by 11,000 people.

Care allowance for pensioners

The purpose of the care allowance for pensioners is to support the domestic living and care of those disabled persons who are in receipt of a pension and aged over 16. This allowance is paid to refund a person whose functional capacity is reduced at least for a year the costs of care and services or special costs.

The income and property of the persons does not affect their entitlement to the allowance. The lowest care allowance is payable to persons who need regular assistance, guidance and monitoring in their everyday routines, household work and when going shopping or whose illness or impairment entails special costs. Increased care allowance is payable to persons who need daily attentive assistance, regular guidance and monitoring, or whose illness or impairment entails considerable extra costs. Special care allowance is payable to people who are in need of constant care and monitoring or whose illness or impairment entails big special costs. In 1998 more than 145,000 persons were in receipt of care allowance for pensioners.

Disability pension

People's entitlement to disability pension is based on their inability to earn a reasonable living by themselves owing to illness. In order to facilitate the transition to working life, a person in receipt of full disability pension can leave his or her pension dormant for a minimum of six months and a maximum of twelve months when trying to work. If the entry into working life does not succeed, a person can again receive a disability pension.

Tax allowance for the disabled

Persons with disabilities are entitled to considerable income-tax allowance. A person is entitled to this tax allowance if he or she has a permanent handicap caused by illness, defect or impairment. The tax allowance for pensioners is directed to a large number of people, of whom only a small part is seriously disabled persons. Owing to small income the majority of seriously disabled persons do not benefit from this tax allowance.

Refund of automobile tax

According to the law persons with disabilities can be refunded the automobile tax included in the price of a car either wholly or partly. The amount varies according to the quality and seriousness of the impairment. Even families of children with disabilities may be entitled to this refund. Automobile tax is refunded yearly to 1,500 persons.

Exemption of self-employed persons from value-added tax

Some disabled adults are self-employed. The exemption from value-added tax covers mainly disabled entrepreneurs engaged in traditional occupations in handicraft and repair sectors. On average 500 - 1000 disabled entrepreneurs benefit to some extent from the exemption from value-added tax.

Rehabilitation of those injured in accidents at work or in road accidents

Employment accident and motor insurance institutions indemnify the costs of rehabilitation when the need for rehabilitation is due to an employment accident, occupational disease or road accident. Insurance institutions have the primary indemnification responsibility. This rehabilitation may be both medical and vocational.

HEALTH SERVICES & UTILISATION

(9) What health services are currently offered to adults with intellectual disability?

Primary Health Care

The responsibility for organizing health care in Finland lies with the local authority municipalities across the country. These can either provide primary health care services independently or join with the neighbouring municipalities in joint municipal boards which set up joint health centre. They can also buy in health care services from other municipalities or the private sector. There are altogether about 270 health centres in Finland (2002 figure). Each health centre can have several units.

Health services are funded mainly from taxation revenue, partly from local taxation and partly from central governments grants. The central government contribution to municipal social welfare and health care expenditure is determined by the population, age structure and morbidity of the municipality plus a number of other computational factors. Around 10 per cent of public health care costs are covered by customer charges.

Specialist Medical Care

The local authorities are responsible for organizing specialist medical care for residents of the municipality. To this end, the country is divided into 20 hospital districts. Each hospital district has a central hospital, five of which are university hospitals. Each municipality must belong to one or other of the hospital districts. The hospital districts organize and provide specialist medical services for the population of their area.

Finland is divided into 16 regional districts, joint municipal authorities for special care, which offer special services for people with intellectual disability including health care. A district centre often includes an out-patient clinic, rehabilitation unit, psychiatric and neurological departments. In general the customers have been satisfied with the special services. However, the system is considered expensive and the service system is changing.

Private Health Care

Public health provision is supplemented by private health care services. They are concentrated primarily in the larger municipalities. Less than 10 per cent of physicians work exclusively in the private sector, but many public health service doctors hold private surgeries outside their regular working hours. There are also a few private hospitals in Finland.

Patients can reclaim part of the fees charged by private doctors from the national health insurance system; a similar system also applies to private dental charges.

The Government Resolution on the Health 2015 public health programme outlines the targets for Finland's national health policy for the next fifteen years. The main focus of the strategy is on health promotion, not so much on developing the health service system. The foundation for the strategy is provided by the Health for All programme of the WHO, which was revised in 1998. The strategy is a continuation of the Finnish national HFA 2000 programme.

Health 2015 is a cooperation programme that provides a broad framework for health promotion in various component areas of society. It reaches across different sectors of administration, since public health is largely determined by factors outside health care: lifestyles, living environment, quality of products, factors promoting and factors endangering community health. The programme has been prepared by the Advisory Board for Public Health set up by the Government. The process involved consultation with specialists, analyses, seminars and group work. Government Resolution on the Health 2015 public health programme. Helsinki 2001. 36 p. (Publications of the Ministry of Social Affairs and Health, ISSN 1236- 2050: 2001:6) ISBN 952-00-0982-5.

Rehabilitation within social welfare and health care

Health care has the main responsibility for the medical rehabilitation of persons with disabilities. Rehabilitation consists of counselling, examination of the need for rehabilitation, different therapies, rehabilitation periods in an institution, adaptation training, rehabilitation counselling and aids. A rehabilitation plan is drawn up together with the client and his or her family. Hospitals and health centres are responsible for arranging medical rehabilitation. There are separate rehabilitation and prosthetic, vehicle and appliance units in central hospitals giving expert help in the area of the whole hospital district. Basic rehabilitation services and basic technical aids are available at health centres. Services can also be purchased from private institutions and professionals or from disability organisations.

Aids are given or loaned to the client. This service also includes instruction in the use of the aid, its replacement and maintenance. Aids are free of charge. Most of the rehabilitation services are free, but for part of them, such as therapies and rehabilitation periods in institutions, the clients are charged a small fee.

Health care is responsible for providing rehabilitation at the initial stage, i.e. acute rehabilitation. Later, social insurance schemes, such as the Social Insurance Institution and employment accident and motor insurance institutions contribute to financing rehabilitation.

Medical rehabilitation of seriously disabled persons

Seriously disabled persons are entitled to medical rehabilitation organised by the Social Insurance Institution, which constitutes either therapy for maintaining working and functional capacity in out-patient care or a period of rehabilitation in an institution. This form of rehabilitation is given yearly to about 15,000 seriously disabled persons, almost a half of whom are children.

Rehabilitation is provided free of charge.

(10) Is there a body of research in your Member State on the health of adults with intellectual disability?

Cite main researchers and areas of research they investigate (not the specific studies themselves – just direct the reader to where the information can be found)

Research

Disability research is carried on e.g. at the Universities of Jyväskylä and Kuopio. There is a Centre for Disability Research maintained by the Foundation for Research on Disability at the University of Jyväskylä. The focus of disability research in Jyväskylä is on studying disability-related sociology and social sciences, special education, neuropsychology, and rehabilitation and physical activities for the disabled. The Centre for Disability Research maintains VAMNET information service (Information and Advisory Services, <http://www.jyu.fi/~vamtutk>), the Finnish Network for Disability Research and takes part in international co-operation through the Nordic Network for Disability Research and EU programmes and international organisations. The Centre for Disability Research arranges education and postgraduate studies for researchers, conferences and seminars.

The Disability Research Unit of the University of Kuopio is orientated towards societal research and its practical applications. It also co-operates and carries out projects with various organisations. The unit plans and co-ordinates, among other things, commissioned research projects as multidisciplinary co-operation, using the expertise of the University of Kuopio and the Kuopio University Central Hospital.

The National Research and Development Centre for Welfare and Health (STAKES) has a research unit on independent living. It focuses e.g. on the quality of aids and information about them and promotes developing ordinary apartments so that older persons and persons with disabilities could live in their own homes as long as possible.

NGOs are also engaged in research activities. The Finnish Association on Mental Retardation studies issues related to the quality of services for disabled persons, rehabilitation methods, municipal services and the shaping of the life span.

The Rinnekoti Research Centre was founded in 1964 to perform out and enhance medical, psychological, social and related research of intellectual disability and developmental disorders of the nervous system.

The publications of The Rinnekoti Research Centre will be found in the following web-page:
http://www.rinnekoti.fi/internal.php?Title_fin=Julkaisut

The research unit of The Finnish Association on Mental Retardation generates diverse data on the life and rehabilitation of people with intellectual disability. In collaboration with the service providers and the service users, the quality of services offered is reviewed. The research results will tell the service providers what impact their services have on the life of a person with intellectual disability and how to develop them so that they eventually meet the users' needs and wishes. With the help of a intellectual disability barometer, the Association keeps track of the status of the intellectually disabled in society. The barometer provides information about housing and care, services, work opportunities and other livelihood activities of the people with intellectual disability. It also gives information on empowerment of the intellectually disabled. The data is gathered from the service users and the service providers.

Library on Intellectual Disability

The FAMR has the most comprehensive library on intellectual disability and rehabilitation of intellectual disability in Finland. It is used especially by researchers, students, and professionals in the field of intellectual disability.

(11) Is there any data on life expectancy among this population in your Member State?

Life expectancy and mortality in intellectual disability

Kristiina Patja, academic dissertation, Helsinki 2001.

FAMR Research Publications, No. 81 Helsinki: Finnish Association on Mental Retardation

This Thesis comprises the first population based study of life expectancy and cause specific mortality of persons with intellectual disability (ID). It is based on a 35-year (1962-1997) follow-up study of a nation representative cohort of 2369 persons with ID between ages 2 and 97 years. The life expectancy had a positive correlation with intelligence quotient. Profound ID was connected with 30% lost of life span throughout the life, but persons with mild ID had a similar life expectancy with the general population. The life span of persons with ID has lengthened generally, but it is depended on the level of ID. The improved life expectancy can be interpreted as a result of improved health care and social support and normalisation.

Life expectancy at birth in Finland, total population is 77.92 years

<http://www.nationmaster.com/country/fin/Health>

(12) Can you provide comparative information on the following for both people with intellectual disability and the general population – prevalence of epilepsy, forms of health promotion such as screening for blood pressure, blood cholesterol, breast screening, cervical screening, testicular cancer screening. Are there other forms of health promotion screening available to people with intellectual disability (such as medication use, oral hygiene, contraception etc.) and how is this information available – in written form, pictures, television adverts etc.

Comparative information on health promotion for both people with intellectual disability and the general population is not available.

Several studies have on the prevalence of epilepsy in the population and among people with intellectual disability are available:

Epilepsy and associated handicaps in a 1 year birth cohort in northern Finland
Eur J Pediatr. 1985 Jul;144(2):149-51. von Wendt L, Rantakallio P, Saukkonen AL, Mäkinen H.
 A 1 year birth cohort in the provinces of Oulu and Lapland in the Northern part of Finland consisted of 12058 live-born infants, this being 96% of all children born in 1966 in this area. Information on morbidity up to the age of 14 years was collected prospectively by means of questionnaires, special examinations and from national and regional registers of hospital admissions and social services contacts. The total number of children with epilepsy, defined as the occurrence of at least one afebrile epileptic seizure, was 208, 113 boys and 95 girls. The cumulative incidences for epilepsy up to the age of 14 years was 17.3 per 1000. Primary generalised epilepsy was present in 63% and partial seizures in 37%. At least one additional handicapping condition, such as cerebral palsy, mental retardation, and visual or auditory defect was present in 74 children (35.5%). Mental retardation was the most frequent additional handicap, being present in 28%, whereas 16% of the children had cerebral palsy. A total of 75% of the children were able to attend an ordinary school. The high frequency of epilepsy in this study, as compared to other studies, is explained by the cumulative registration of the cases and a high degree of ascertainment of cases with epilepsy.

Epilepsy in children: prevalence, disability, and handicap.

Epilepsia. 1992 May-Jun;33(3):444-9. Sillanpää M.

Little is known about the handicapping effect of epilepsy without other neurological deficits on an epileptic individual's life. The purpose of this study was to collect information on the occurrence of disabilities and handicaps in an unselected population sample of children, 4-15 years of age, and to compare the results with matched controls. The prevalence of epilepsy in the study population was 0.68% (143/21, 104). Time elapsed from last seizure was at least 1 year in 62.1% of the cases. There was marked neurologic comorbidity in the children with epilepsy; an accessory neurological deficit was found in 39.9%, the most frequent neurological impairments being mental retardation (31.4%), speech disorders (27.5%), and specific learning disorders (23.1%). A handicap was experienced in 20.7% of children with epilepsy only; i.e., with no other neurologic impairments, compared to 0.9% of matched controls. This means a 21.7-fold (95% CI, 6.3-74.5) risk of the occurrence of a handicap in children with epilepsy compared to controls. Orientation and social integration handicaps were significantly more frequent in children with epilepsy only compared to controls. Occurrence of communication disability, situational disability, or satisfactory to poor economic status of the family were the independent predictors of the occurrence of a handicap in children with epilepsy only.

Prevalence, classification, and severity of epilepsy and epileptic syndromes in Children

Epilepsia. 1997 Dec;38(12):1275-82. Eriksson KJ, Koivikko MJ.

PURPOSE: To determine the point prevalence of active childhood epilepsy in a defined area and evaluate the usefulness of ILAE classification of seizures, and epilepsies/syndromes with special interest in severe epilepsies. **METHODS:** By using the latest ILAE International Classification of Epileptic Seizures (ICES, 1981) and Epilepsies and Epileptic Syndromes (ICE, 1989), we determined the age- and sex-specific prevalence rates of epilepsy, type of seizures, epilepsies, and recognizable epileptic syndromes, as well as the proportion of severe cases in each seizure/epilepsy/syndrome category in all children 0-15 years of age from a geographically defined area in Finland. All medical records, neurophysiological recordings and available clinical data were reviewed retrospectively. **RESULTS:** Point prevalence of active epilepsy on December 12, 1992 was 3.94 per 1,000. According to ICES/ICE, we were able to classify 96% of seizures and 90% of epilepsies and syndromes. Generalized seizure and epilepsy/syndrome types were more prevalent in children 0-6 years of age and partial/localization-related in children 6-15 years of age. Epilepsy was intractable in 17% of all cases and correlated significantly with symptomatic etiology and early onset of epilepsy, as well as with additional neuroimpairments.

CONCLUSIONS: A considerable number of cases fell into the nonspecific categories of ICE,

which limits the value of present epilepsy/syndrome classification in terms of prognosis, prediction, and indication for special investigations in individual cases. A number of intractable cases was relatively low, indicating good prognosis in many childhood epilepsies, especially when additional neuroimpairments are absent.

A population-based study on epilepsy in mentally retarded children.

Epilepsia. 2000 Sep;41(9):1214-20. Airaksinen EM, Matilainen R, Mononen T, Mustonen K, Partanen J, Jokela V, Halonen P.

PURPOSE: This study presents data on cumulative risk of seizures, cause, comorbidity, and remission of epilepsy among mentally retarded (MR) children followed until the age of 22 years. **METHODS:** A total of 151 MR children were identified at the age of 8 or 9 years by screening four birth cohorts of 12,882 children born from 1969 to 1972 in the Finnish province of Kuopio. Information about epilepsy was gathered longitudinally when children were 9 to 10, 17, and 22 years old. The guidelines for epidemiological studies on epilepsy proposed by the International League Against Epilepsy were followed. **RESULTS:** By the age of 10 years, 29 of the 151 MR children (19%) had epilepsy. The cumulative risk for epilepsy at 22 years was 21%. The probability of developing epilepsy was increased fivefold in severely MR children compared with mildly MR children, i.e., in 27 of the 77 severely MR children (35%) versus 5 of the 74 mildly MR children (7%). Postnatal causes of mental retardation or association with cerebral palsy increased the risk for epilepsy, especially in the mildly MR children. When these risk factors were not present, the mildly MR children exhibited only a 3% risk for epilepsy, whereas the respective risk was about 10-fold in severe mental retardation. The cumulative probability of epilepsy being in remission for 5 years by the age of 22 was 32%. **CONCLUSIONS:** The cumulative risk of epilepsy varies according to the severity and the cause of the retardation as well as the presence of additional disabilities. The cumulative probability of epilepsy remission tended to increase with age.

(13) Is there any disability specific training for health professionals – such as modules on undergraduate programmes etc? GP, Dental, Psychiatry -

Staff Training and Education

The FAMR offers continuing education for staff working with the rehabilitation and care of the intellectually disabled. In addition to national training and education, the range of its services includes interdisciplinary education tailored to meet the wishes and needs of client organisations.

In addition to theoretical knowledge, the trainers and teachers of the FAMR have strong competence and experience in practical work. Consequently, any new information available is easy to apply to routine work in the work communities.

Ketju, Magazine on Intellectual Disability Issues

Ketju writes about current issues in the field of intellectual disability. The topics discussed are services for the people needing support in learning, understanding, and communicating. Efficient news reporting and real-life stories come together on the pages of Ketju. The articles are in the form and content to give impetus to developing one's own work. Ketju is published six times a year.

In Finland a child or adult neurologist, child, youth or adult psychiatrist, paediatrician, geneticist, internist or specialist in general practice may achieve special competence in intellectual disability medicine after working three years in public services and passing the examination held by a board

of examiners. The number of specialists in the field of intellectual disability medicine is about 60. The Finnish Society of Intellectual Disability Medicine has about 140 members and was founded in 1982. The society organises two annual congresses.

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