



People with Intellectual Disabilities in Finland

PKN (PERTTI KURIKAN NIMIPÄIVÄT) WON THE NEW MUSIC COMPETITION IN FINLAND. PHOTO: ANTON SUCKSDORFF / VLE

There are around 40 000 people with intellectual disabilities in Finland, amounting to 0.8 % of the population.

The laws that regulate the main services include, for example, the Social Welfare Act, the Act on Special Care for the Mentally Handicapped and the Disability Services Act, the latter two of which are in the process of being combined. Legislation on work and day activities and work coaching is also currently under reform. Finland still hasn't completed the ratification of the UN Convention on Rights of Persons with Disabilities. The Parliament has approved the Convention, but before ratification, amendments need to be made in legislation concerning certain rights of self-determination. The municipalities look after the provision of services for people with intellectual disabilities.

- **FAIDD (The Finnish Association on Intellectual and Developmental Disabilities) regards it as important that the amendments in legislation concerning rights of self-determination will be made and Finland can proceed to ratify the UN Convention without delay.**

- **The next sitting government needs to continue the process of combining the Act on Special Care for the Mentally Handicapped and the Disability Services Act so that Finland will have one law to secure equal services for all people with disabilities.**

WHEN A CHILD WITH INTELLECTUAL DISABILITY IS BORN IN THE FAMILY

FINLAND HAS ADOPTED national best practice guidelines on informing families of their child's disability, based on the Irish model:

www.jaatinen.info/files/Ensitiето_suomennos_Irlanti.pdf

When a child has been diagnosed with an intellectual disability a special care program and service plan is prepared for her or him. It articulates what kind of support the individual child or family needs and how the municipality will provide it.

CHILD DAYCARE

TODAY THE DAYCARE is usually provided in ordinary daycare centers and groups, with the support of teachers for children with special needs.

A child can receive rehabilitative daycare if this is seen to further her or his development. This care is free of cost to the family, unlike child daycare in Finland in general.

A child is entitled to be accompanied at the daycare center, if needed, by a personal assistant.

The parents of a disabled child can also receive at regular intervals temporary care assistance, for example, during weekends to get a break from caring for the child.

FINANCIAL SUPPORT FOR FAMILIES

IF FINANCIAL STRAIN is caused to the parents by their child's disability, they may receive up to 420 euros a month in disability allowance. They may also receive compensation if a child has special clothing or dietary needs that create extra costs.

If the parents are the family caregivers of a disabled child they are entitled to a family caregiver's allowance. The amount of the allowance varies in different municipalities, but it is at least 384.67 euros a month.

BASIC EDUCATION

COMPULSORY EDUCATION APPLIES to all children with intellectual disabilities. For children with intellectual disabilities it begins a year earlier and they start preschool at the age of 5. According to the latest statistics there are nearly 11 000 students to whom extended compulsory education applies.

Students may receive support at schools according to their needs in three tiers: universal, targeted and intensified. Of all students in basic education 13.8 %, altogether 74 677 persons, received targeted or intensified support in 2013 (only a part of them were students with intellectual disabilities).

The prevailing principle is inclusion: the aim is that students who need special support could study at their own local schools, in ordinary teaching groups. In practice the principle of inclusion concerning children with intellectual disabilities is not realized at school age nearly as well as in daycare; the studying takes more commonly place in special education groups or as only partly integrated into mainstream teaching.

Only 19 % of the students who received special education performed their studies entirely in mainstream

education groups in 2013. 42 % of them performed their studies entirely in special education groups, some of these in special education schools.

Children with intellectual disabilities are to be offered morning and afternoon activities outside the school day, regardless of the student's age. With mainstream students this only applies to those on first and second grade.

- **FAIDD regards it as important to improve the opportunities of children with intellectual disabilities to study inclusively at their own local schools. This means that municipalities need to allocate sufficient resources for special education and, for example, the hiring of learning assistants at schools.**

VOCATIONAL EDUCATION AND TRAINING

AFTER BASIC EDUCATION many young people with intellectual disabilities continue their education at upper secondary level. This may take place either in the form of adapted teaching at ordinary vocational schools or within special education vocational schools.

There are no exact statistics on students with intellectual disabilities who have received vocational education. The most common fields of vocational education are home and institutional economics and cleaning services, followed by the hospitality field and property maintenance.

Over 21 000 students received vocational special education in 2012, amounting to 7.7 % of all students in vocational education. Only a part of the recipients of vocational special education are students with intellectual disabilities, and they are not differentiated in the statistics.

A little under 2 700 people studied at vocational special education schools in 2012. 1 700 students studied in special education groups at vocational schools. Nearly 17 000 students received special education in mainstream education groups. These statistics do not differentiate how many of them were students with intellectual disabilities.

Students with intellectual disabilities are entitled to use learning assistant services, interpreter services and, if needed, a personal assistant to support them in their studies.

- **FAIDD especially wishes to develop supported apprenticeship training.**
- **Vocational education should be available to everyone after basic education.**



PHOTO: TIIA SANTAVIRTA / YLE

EMPLOYMENT

THERE ARE 25 000 people with intellectual disabilities of working age in Finland. Only 400–500 of them are wage earners. An estimated 3 000 of them are potentially employable.

- **More work coaches are needed in the municipal service system to support both the employees and the employers so that a larger part of the employable persons could gain payable employment in the open labor market.**

13 000 people with intellectual disabilities are engaged in sheltered work or day activities in activity centers. Transportation to the site is free of charge.

More than 2 000 people with intellectual disabilities are engaged in so-called community employment. The work takes place in ordinary places of employment. It is not however based on regular contracts of employment but regarded as a social service, which is why the worker is paid, instead of regular wages, a “daily allowance”, approx. 5 € per day.

- **FAIDD regards community employment as a drawback that should be overthrown or turned into a temporary arrangement, always aimed at normally paid employment.**

SUBSISTENCE

A MAJORITY OF adults with intellectual disabilities are on pension. Without any employment background, the pensions are small and the income of most of the people with intellectual disabilities is low. The minimum monthly amount of pension is now 743.38 euros.

According to a recent study, households with an intellectually disabled family member regard themselves clearly poorer compared to other households.

- **The basic income of people with intellectual disabilities needs to be increased by raising the minimum amount of pension and developing opportunities to enter paid employment.**

- The system of combining paid and pensioner income should be made more flexible so that the pension is not withdrawn if it exceeds a certain income level, as is current practice, since it does not encourage employment.

HOUSING AND SUPPORT FOR DAILY LIFE

1 300 PERSONS WITH intellectual disabilities live in institutions. 17 000 persons with intellectual disabilities live with their families, 9 000 of them are adults. Around 11 000 persons with intellectual disabilities live in serviced housing, 9 000 of them in group housing, and a little over 2 000 in supported housing.

The aim of the KEHAS program of the Government of Finland is that by 2020 no person with an intellectual disability would live in an institution. The goal is to produce 3 600 new apartments for intellectually disabled persons by the end of 2015, amounting to 600 apartments per year.

- **FAIDD firmly proposes that any person with an intellectual disability must have the right to choose for themselves where, how and with whom they live. This is consistent with the requirements of the UN Convention on Rights of Persons with Intellectual Disabilities. In practice the possibilities to choose are not realized in the manner stipulated by the convention. It is often the service supply that determines where a person with an intellectual disability lives. In some municipalities there may only be one option available, which limits the possibility of choice. The most common forms on offer are group housing type solutions.**

- **People want to live in normal apartments and normal neighborhoods.**

People with intellectual disabilities need support in their daily lives. In group housing the staff of the housing unit helps them with their daily activities. There are various options for how housing could be provided for those persons who can and wish to live more independently. People with complex disabilities are entitled to personal support at and outside home. In practice the provision of personal assistants has been insufficient.

- **No one is too severely disabled to be able to live at a home of their own – it is a question of how the assistance and support are organized. The support needs to be customized according to where the person lives.**

- The system of personal support needs to be expanded to also include people with intellectual disabilities.
- Personal budgeting should be included as one way of organizing services so that people with intellectual disabilities could gain more influence over the services offered to them.

CITIZEN RIGHTS AND LEGAL CAPACITY

ALL FINNISH PERSONS with an intellectual disability have the right to vote and stand for election.

A guardian may be assigned for a person with an intellectual disability if she or he is not capable of guarding her or his own interests or looking after her or his own affairs. The guardian is appointed by the magistrate. The parents are automatically assigned, with no separate legal appointment, as the guardian if the person in question is a minor.

The legal capacity of the person under guardianship is limited. Most commonly the task of the guardian is to only look after the financial affairs of the person under guardianship in a spirit of cooperation, without interfering in her or his decision making powers otherwise.

PROVISION OF INFORMATION

Participation in society requires provision of information in an understandable form, for example, in easy-to-read or plain language. A government program has been launched in Finland aimed at improving the intelligibility of official language. Some public actors have also set out to improve, for example, the accessibility of their websites and to offer information in plain language.

- **In FAIDD's assessment there are half a million people living in Finland who would benefit from the provision of information in plain language – many of whom are not intellectually disabled.**

AGEING PEOPLE WITH INTELLECTUAL DISABILITIES

THE LIFE EXPECTANCY of people with intellectual disabilities has grown during the past decades, consistently with the mainstream population. As the entire population has aged, the number of ageing people with intellectual disabilities has also grown. The share of the Finnish population aged 65 or over is 0.4 %.



PHOTO: TIIA SANTAVIRTA / YLE

- **The question of ageing among people with intellectual disabilities has not been sufficiently taken into account in the service system. Ageing people with intellectual disabilities need meaningful day activities, according to their functional capacities. Health care services also need to be developed to better serve the needs of ageing people with intellectual disabilities.**

PKN

THE STATUS OF people with intellectual disabilities in Finland has clearly taken a turn for the better in recent decades. They have gained visibility in society: the popular TV soap series “Salatut elämät” (Secret Lives) has featured actors with intellectual disabilities and the reality series “Toisenlaiset frendit” (Different Friends) has been followed by a huge number of viewers.

The band Pertti Kurikan Nimipäivät (PKN) has made an unforeseen public breakthrough not only with their music but also through the documentary

“Kovasikajuttu” (The Punk Syndrome), and now the Eurovision Song Contest.

The NIMBY (Not In My Backyard) effect has been seen to occur in Finland when group housing is built for people with intellectual disabilities amidst mainstream housing. The residents have protested against people with intellectual disabilities moving into their neighborhoods. A YIMBY (Yes In My Backyard) movement has emerged as a counterforce to this trend, welcoming people with intellectual disabilities and drawing momentum from, for example, social media.

The election of PKN as Finland’s representative in the Eurovision Song Contest in Vienna is a positive sign of the attitudes of ordinary Finns. FAIDD rejoices over the band’s success and wishes them good luck in Vienna.

- **We are working towards the goal that people with intellectual disabilities, who still in many ways remain in the margins of society, could enter the mainstream, like PKN. We promote inclusion in all spheres of life.**