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ABSTRACTS FOR WORKSHOPS

J. Dialogue and disability issues

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Accessibility is a human right

During the past few decades in Finland, it has been possible gradually to alter planning and building practices in such a way as to take better account of the needs of different kinds of people.

In 1973, a clause was added to the Finnish Building Decree that stipulated, for the first time, that planning should also give adequate consideration to the needs of people with impaired mobility or orientation skills. In 1978, a group of associations of disabled people lodged an official complaint with the Chancellor of Justice, concerning the absence of any lift in the town hall of Kauniainen (a small town near Helsinki); this complaint resulted in an acknowledgement of the need for a lift in public buildings even if they only have two storeys, and provisions and guidelines to this effect were incorporated in the relevant legislation.

Gradually, the effect of the decree began to be seen in new buildings. Disabled people still had to lodge complaints many times, especially when attempts were made to avoid the lift requirement.

New Building Regulations and Guidelines F1 and G1 came into force 1.3.2005. In them the accessibility regulations have become better than before. Disabled people have begun to influence the decision-making process more actively by uniting their forces. Largely for this reason, public opinions and priorities have gradually become softer and more tolerant. And this in turn has affected the political will to make legislative changes.

However, at a time of social crisis, mass unemployment and economic difficulties, there is always the fear of a regression in social development and a return of harder values. This means that all disabled people should continue to be as active as possible, in cooperating with other disabled people and with those who plan and make the decisions in society.

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Harvinaiset – the Finnish Network for Rare Diseases

A disease or a disorder is defined as rare in Finland, when it affects less than 1 in 10 000 citizens (a bit over 500 Finnish people at the most). In the European Union the ratio is 1:2000. Rare diseases are disabling and people with a rare disease face great difficulties in getting a diagnosis, finding information, getting proper health care and services as well as leading a normal life. Peer group support is especially important among people with rare diseases.

Harvinaiset-network consists of experts in 16 major non-governmental organisations (NGOs). The network has no official, judicial stand but works as a partnership network to coordinate Finnish rare disease work.

The prime goal of the network is to improve the conditions of people with rare diseases. It is essential to identify the problems the people in these groups face as well as to cover their needs for service. The Resource Centres work together with specialists, service providers and disability/patient organisations. The network has made public statements and contentions as a part of its mission of raising public awareness and influencing the decision makers. One of the most important tasks of the network is to facilitate the patient groups to share their experiences and best practices.

The Harvinaiset-network has been working on a major project called One Door – Many Windows. The goal of the project is to create a unique Internet portal focusing on accessibility, reliability and interactivity. This project also aims to unite to co-operation the major groups and organisations in Finland doing important work in the field of rare disorders and disabilities.

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Assistentti.info – Personal assistance for people with disabilities

Assistentti.info is a national project to coordinate the various personal assistant services that exist for people with extensive disabilities in the whole of Finland. The project promotes the professional skills of various stakeholders of the system and raises awareness about the system. Assistentti.info is coordinated by The Threshold Association (Kynnys ry, Independent Living Centre in Finland).

Assistentti.info is a network consisting of associations and organisations of people with different kind of disabilities: physical disabilities, learning disabilities, visual impairments etc, organisations of users of personal assistant services, organisations of service providers, organisations of social workers, educational institutes and other expert bodies. The network has four working groups: training, legal issues, research and development, support to personal assistants. The network has organised study trips to Sweden and to New York, USA.

The network has organised annual training seminars on the personal assistance system and independent living philosophy. There have also been several workshops on more specific issues such as human rights, the role of social services, housing and personal assistance, etc. The training events are held in various parts of Finland, not only in the capital Helsinki.

One part of the project was a training program on leadership skills for disabled people who employ personal assistants. The program was organised in cooperation with the University of Helsinki. The participants were required to complete a final paper that discussed a topic related to the system. The papers will be useful for other disabled employers in future.

The network has a counselling service where experts answer questions through telephone or through e-mail. There is also a special web-based service for professionals in the field of social work, with a lawyer answering the questions.