

The activities of the Estonian Support Union of the Deafblind in 10 years

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Tallinn

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In its activities, the Support Union has been following the objectives specified in its articles of association. These are:

- ✘ protecting the rights of deafblind people
- ✘ training people who work with the deafblind
- ✘ rehabilitation services to children and adults
- ✘ gathering necessary information on deafblindness
- ✘ initiating co-operation in areas connected to deafblindness

I shall review our activities according to these objectives.

On the initiative and with the support of the **Nordic countries**, work with deafblind people began in Estonia in 1993. Marjaana Suosalmi and Inger Rodbroe were the first specialists to share their experiences in this field.

In our first years of operation, the Support Union received a lot of help from the **Estonian Federation of the Blind**. In time, our co-operation network expanded; our neighbours from Finland make up a significant part of this network. The Support Union of the Deafblind was included in the EU PHARE LIEN project for visually impaired people in Estonia and Finland. Within the framework of this project, the needs of deafblind people were identified and further action was planned for.

Work with children began with the support of the German Lutheran Church. Upon identifying the situation of deafblind children it turned out that there were deafblind children in children's homes and kindergartens all over the country where the staff lacked the necessary skills to work with them. Thus the children did not receive an education suitable to their abilities.

At a round table led by **Toomas Sepp** the idea to open a class for deafblind children at the Porkuni School for the Deaf was born. The chairpersons of the Federation of the Blind and the Support Union of the Deafblind presented this proposal to the Minister of Education in a joint letter sent in February 1998. Teacher training possibilities were also offered. The staff of **Jyvaskyla Rehabilitation Centre** provided help with the trainings and visited Porkuni several times together with the employees of the Support Union. Today, there are two classes at Porkuni School for deafblind and multidisabled blind children. Training of the employees is ongoing – the staff of Porkuni School actively participates in the trainings organised with the help of the USA HILTON/PERKINS programme.

Avo Hein, the principal of the school, is a member of the Support Union's board and takes part in furthering our activities.

In our work with children, we are paying increasingly more attention to **early intervention** in a child's development. In this respect, the Support Union values in particular its co-operation with the **Tallinn Children's Hospital**. A regular co-operation has evolved from our first contacts with **Dr Liis Toome**. Head of department **Dr Adik Levin** has shared his experiences with our co-operation partners from the HILTON/PERKINS programme. Physical therapist **Hille Maas** shares her experiences at the trainings organised by the Support Union, participates in the work of a rehabilitation group and works with our children.

The children's department of the **Finnish Federation of the Visually Impaired** has been of great help to us in training teachers. Employees of the Finnish organisation have carried out trainings in Estonia. The employees of the Support Union have received practical training and participated in courses carried out in Finland.

For the fifth year, the Support Union receives support and professional help in the framework of the **USA HILTON/PERKINS programme**. A significant part of the project concerns the training of employees as well as translating and publishing training materials. Guidance and training of parents is an also area of importance. Parents take part in the trainings alongside employees.

In order to offer the children as much help as possible, the Support Union is involved in close co-operation with the educational institution where the children study.

Together with **Karin Saare**, director of the **Tallinn Linnupesa Kindergarten**, we try to improve the educational possibilities offered to pre-school as well as school-aged visually impaired children in Tallinn.

Kirsti Nigesen, director of the **Old Town Educational College**, does everything in her power in order that blind children integrated into the school could have a smooth education.

Tamara Kazakova, principal of the Juhkentali Upper Secondary School, has provided the possibility to integrate Russian-speaking blind children.

Recently the **Tallinn Education Department** has been searching for different solutions to improve the educational possibilities of visually impaired children. With the active help of **Tiina Käsi**, specialist of the Education Department, a consultation group started in Linnupesa Kindergarten in autumn 2003, where children studying in ordinary schools receive professional help and the development of deafblind children is supported in every possible way. Hopefully our co-operation with the new specialist **Urve Raudsepp-Alt** will also prove to be a productive one. A good foundation has been laid to that end and today she will also give a presentation at our seminar.

ADULTS

Active work with deafblind adults was started in co-operation with the Finnish Deafblind Association thanks to the long-time dedicated activities of **Terhi Pikkujämsä** who has inspired and encouraged us in this work.

In 1999 adaptation courses commenced on Terhi's initiative. By today, these have become annual courses where deafblind people and their families can receive necessary information and instruction for coping in everyday life. We have started to use **tactile sign language**, which is one of the most important forms of communication for the deafblind. You will see how it is used at the seminar today.

Finnish deafblinds also took part in the courses and our members **Kalju Arukase** and **Henn Kungla** have attended conferences in Finland.

Our co-operation has been going on for five years and in addition to organising adaptation courses, we were able to translate various training materials and publish publications during this time. I have here with me **Helen Keller's "THE MIRACLE OF LEARNING", techniques for guiding deafblind people, in Braille (Estonian, Russian)**.

Money for these activities was received from NUD (the Nordic Staff Training Centre for Deafblind Services) that is financed by the Nordic Council.

The **Estonian Library for the Blind** provides us with materials in Braille. The head of the library **Priit Kasepalu** is always helpful in preparing teaching materials as well as other necessary materials for children.

In addition to the Nordic Staff Training Centre, **ARLAINSTITUUTTI**, the Finnish Vocational Training Centre for the Visually Impaired has helped us with the training of specialists working with both children and adults. **Anne Lumiste** has carried out various trainings. We consider the training of mobility instructors, the costs of which were partially covered by **ARLAINSTITUUTTI** and the Estonian Ministry of Education, to be especially important. **Kai Kukkk**, adviser at the Ministry of Education, has supported our training activities and searched for possibilities to solve educational problems.

Support Union underwent a positive change in 2001 when it joined the **Estonian Chamber of Disabled People**. This made it possible for us to receive state funding through the **Foundation for Disabled People** to carry out various projects. The manager of the Foundation, Genadi Vaher, is always willing to help the Support Union develop its strategies and has supported us in our activities.

As a member of the Chamber, the Support Union can introduce its activities to a wide circle of people and find joint solutions to common problems with other disabled people's organisations. **Helve Luik**, spokesperson for the Chamber, and its manager **Lissi Kurg** have supported our activities in every way. Although we are a very small organisation, our suggestions have been heard and considered.

As a result of the active co-operation between the Chamber of Disabled People and the **Ministry of Social Affairs**, a lot of attention has been recently paid to the rehabilitation of disabled people. **Küllli Roht**, representative of the Ministry of Social Affairs, has done a remarkable job in identifying the rehabilitation needs of the Estonian disabled people and we hope that this will form a strong basis for developing a rehabilitation system for the disabled.

As one of the objectives specified in our articles of association, the Support Union has been developing **rehabilitation** activities. With the encouragement of **Eha Leppik**, specialist of the Ministry of Social Affairs, the Support Union applied for a licence to provide rehabilitation services. The result was a positive one and the Support Union was given a licence to provide rehabilitation services in January 2003, which also imposes new requirements and obligations on the Support Union.

To finish my speech, I would like to give a short overview of the Support Union's plans for the future:

- ✘ identify the number of deafblind people in Estonia
- ✘ develop rehabilitation activities and improve the quality of services offered
- ✘ contribute to the creation of new educational possibilities
- ✘ involve deafblind people and parents of deafblind children in the activities of the Support Union, although a number of parents are actively involved in our activities.

For the entire 10 years since the formation of the Support Union, our chairperson has been **Margarita Rägapart**, mother of a deafblind child.

I have mentioned the names of several people who have contributed to the activities of the Support Union. I would like to thank you all for your help and support.

However I have not mentioned the names of the family members of our children and adults:

- the parents who have raised and are still raising their deafblind children,
- the husbands and wives who are there for their deafblind spouses
- and all the other partners whose help our members rely on.

On behalf of the Support Union, I would like to thank them all and wish them the emotional strength to bring sincere warmth and a sense of security into the lives of our deafblind children and adults.

I hope you will have a pleasant day at the seminar!