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To  
Estland konference

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From  
Marianne Smedegaard

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Subject  
Oplæg

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**PRESENTATION OF THE CO-OPERATION PROGRAM CONCERNING  
DISABLED CHILDREN AND THEIR FAMILY.**

18 October 2006

Let me very brief introduce myself.

I am from Denmark, work since January last year in NSH office in Stockholm.

I am educated as a social-worker. In the last 17 years before I came to NSH I was Head of department of handicap Welfare in the county of Funen, Denmark. During this period I was responsible for running projects developing institutions for disabled people in Stettin and Krakow in Poland and in Kaliningrad.

I am project manager in developing the co-operation program aimed at children with disabilities and their family in the three Baltic countries and Northwest-Russia.

The co-operation program is a three-years program, which will be carried through in the period from 2006 until 2008.

Knowledge about and commitment to a human rights-based approach is a key element in the program. This also includes knowledge of the social charter of the council of Europe and UN standard Rules on the Equalization of Opportunities for Persons with disabilities. In light of ongoing processes aimed at developing a new UN convention and a new Council of Europe Action Plan and a new Nordic Design for all action Plan it is desirable to establish a platform for dialogue and exchange of ideas and experiences between key persons in different countries who are tied to the implementation of these values and principles at a national and a regional level.

On a more concrete level the aim is to establish local projects. The aim of these projects will focus on

- developing local based services, which makes it possible for children with disabilities to live at home with their parents, when this will be the best for the child
- to improve the quality of life in the present institutions
- stimulate to close down big institutions over time.

The background for this co-operation program is a conference "Human rights disability children" which took place in November 2004 under the Norwegian Chairmanship in The European Council

and with representatives from 35 countries The conference took starting point in two of the European Council`s most important areas, human rights and social solidarity The congress highlighted the situation for children with disabilities in childrens rights perspective.

The result of the conference was a number of concrete initiatives, among others:

- set up an expert-group, which has to prepare suggestion about recommendations and guidelines to prevent institutionalisation and to promote integration of disabled children in mainstream services and in the society.
- Organise a co-operation between Nordic council of Ministers and the council of Europe, to improve the situation concerning children with disabilities and their family in the Northwest-Russia and the three Baltic countries.

The Norwegian Labour –and Social department granted money for follow up. It was stressed that it should be used to analyse the possibility of preparing a 3-years co-operation program aimed at Northwest-Russia and the three Baltic countries focused on disabled children and their families.

In 2005 was made a preliminary study (pilot study). In this study were gathered information about the situation in the different countries, pointed out ongoing activities, identified and made contact with possible partners and looked closer on contents, organisation and financing of a future co-operation program.

In march last year I went on a trip to visit those countries and in collaboration with the Nordic council of Ministers offices I had meetings with authorities, with NGO`s with professionals and other key persons. I also visited some institutions for disabled children. At my visit here in Estonia I had a meeting with representatives from ministries, and NGO`s.

The aim of this process has been divided into two parts

- a dialogue between the authorities and others to develop a concrete platform for co-operation around children with disabilities and their family, which takes its starting point in the wishes and needs in each country.
- To clarify in which way this co-operation should be organised and regulated.

As to the first point the contact with the authorities showed that in very highly extent was given consent to the aim written in our platform for a further dialogue with the relevant countries. When it comes to concrete initiatives the priority is different in the different countries.

As to the second point, how to organise the work NSH has suggested that a wide compounded working group or steering group is set up in each country. This group has the responsibility to clarify which initiatives and concrete project should be worked with.

The organisation of this co-operation program is decided to be as following:

- NSH is the secretariat
- The project manager
- A reference group should be set up.
- Working group/steering group

- Project`s should be developed in state, county an municipal level.

In Estonia this working group decided to held this conference "social well-Being of a Disabled Child" as a beginning of the co-operation program.

And here we are- at the beginning of the conference –at the beginning of the 3 years co-operation program.

My colleague Lea Stenberg from Nordic development centre for Rehabilitation Tecnology, which is a subsidiary of NSH and I have only met very competent, very committed and very motivated people on all levels. Many things have started up within this area. The legislation shows that there is a political will towards developing the disability area.

It is you who lives here in Lithuania who know what is the need for the future concerning disabled children and their family, within the frame of the co-operation program. Lea and I can as project managers in a close dialogue with the steering committee try to use the co-operation program as effectively as possible to support your strategies in this field.

I hope that this co-operation program and the start of different concrete projects will support the track, in the direction which you want to follow in Estonia.

I want to thank the State of Estonia for financial support to the conference, I want to thank the Nordic council of Ministers office, director Caritta Petterson, and adviser Merle Kuusk for their support and co-operation in arranging this conference. At last but not at least I would also like to thank the steering committe for their engagement, their enthusiasm in the discussions and for sharing their experiences and knowledge in our very interesting steering committee meetings and for their hard work planning this conference.

I am looking forward to continue the cooperation with Estonia.

Thank you for your attention