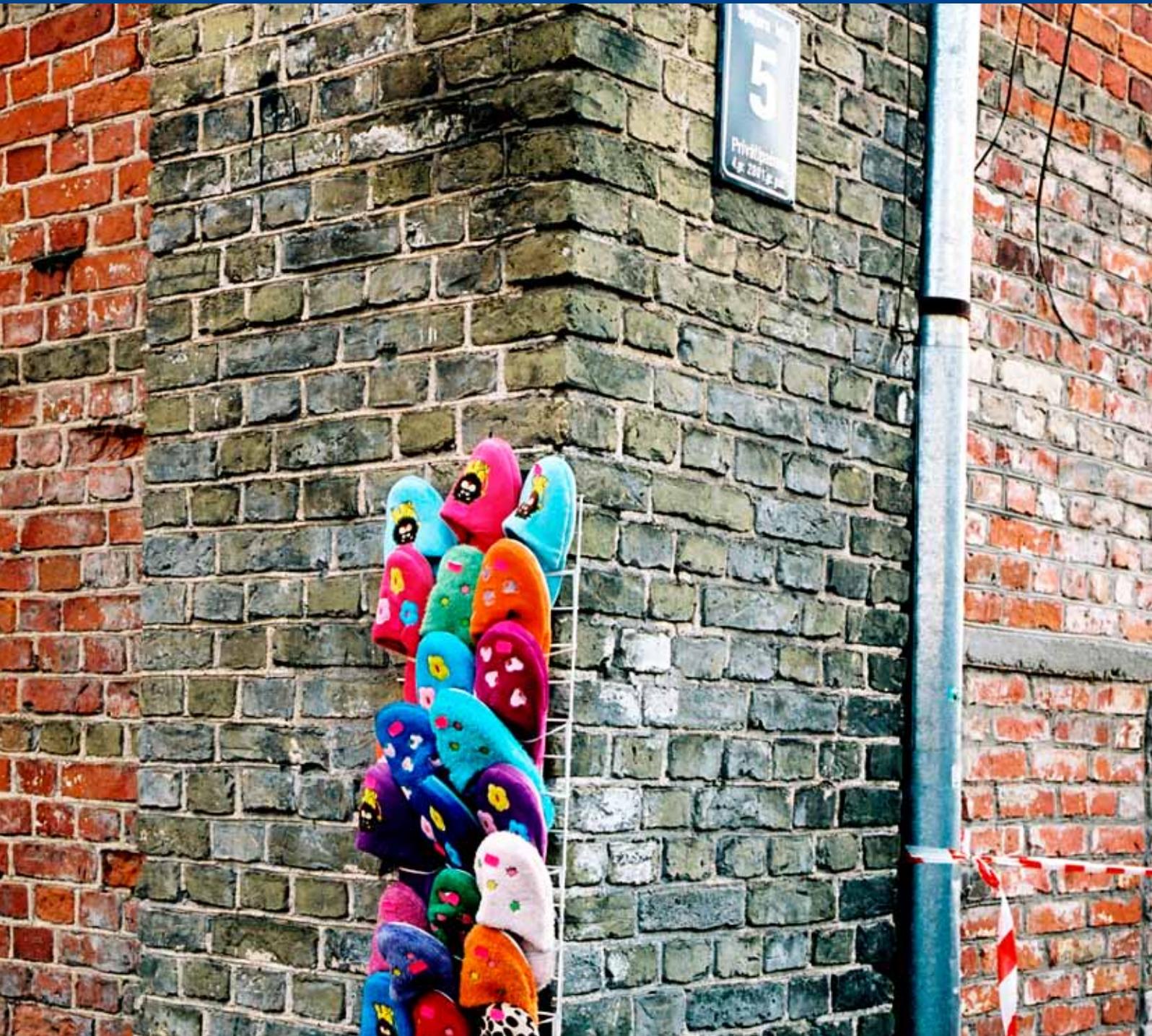




Nordic Centre for Welfare and Social Issues

Bente Ramsing Özgür, 2010



Final report

A One Year Project with Focus on Deafblindness
in Kaliningrad, Lithuania, Latvia and Estonia

Final report
A One Year Project with Focus on Deafblindness in
Kaliningrad, Lithuania, Latvia and Estonia

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Project in the Baltic States and Kaliningrad

1. Abstract

This report is the conclusion of a one year project in 2009, which had the aim to spread awareness and knowledge on deafblindness in northwestern Russia and the three Baltic states. The project was initiated on the basis of a former cooperation with these countries dating back to 1992 onwards.

Kaliningrad, Lithuania, Latvia and Estonia are widely different in terms of population, culture, organization and political structure. Therefore, it was important from the beginning to find out which context was the right basis for the project in each country. Therefore, strategies, plans and aims were agreed upon with key persons in each country and the project differed in the various countries. I believe this to have been a very important factor for me to carry the projects through in such good cooperation and with such good results in all the countries.

In Kaliningrad, I worked on the detection and assessment of deafblind children and held two seminars on deafblindness, identification, development of communication and didactic organization.

In Lithuania, I worked on organizing the work for deafblind people, held two seminars for professionals and gave guidance to the professional staff in the deafblind department on assessment and observation.

In Latvia, I held two seminars of two days each for professionals; one for people who work with children and one for people who work with adults.

In Estonia, I had small guidance projects on four children spread all over the country and held a large seminar for professionals. On top of that, I participated in a TV program which was shown on one of the biggest TV-channels in Estonia.

As an end of the one year project, I arranged a course at the Danish branch of the Nordic Centre

for Welfare and Social Issues with five participants from each of the countries involved in the project.

The course turned out to be a great success and the participants were actively involved in discussions and have subsequently expressed how much they have gained from the course.

The report gives recommendations on how each of the three countries and Kaliningrad can keep on supporting professional work with deafblind people or establish cooperation in those countries which are already active.

The aim of the project was to spread awareness and knowledge of deafblindness in each country. If I should give a guess, then I think I have contributed with knowledge on deafblindness to more than 300,000 people through TV and approximately 100 professionals in Estonia, 200 in Latvia, 100 in Lithuania and 100 in Kaliningrad. This means that the project has contributed to increased awareness of deafblindness among approximately 500 professionals and 300,000 laymen. Subsequently, I think I have revealed a growing need in all the countries for more specific knowledge on deafblindness. In Lithuania and Estonia, where people already work goal-oriented on deafblindness, I have contributed with additional knowledge as well as being able to reach professionals who had not been aware of the disability earlier.

Finally, I have been in contact with government departments and educational institutions in all of the countries, which thereby ultimately have become aware of the fact that deafblindness is a distinct disability and that people with deafblindness have distinct needs.

Since the project lasted one year, it is from now on up to the professionals to formulate their wishes for a continuation of the cooperation and seek continued financial support.

2. Introduction and background

This report is the conclusion of a one year project with the aim of spreading awareness and knowledge on deafblindness in northwestern Russia and the three Baltic states. The project was started on basis of the following:

In 1992, the Nordic Staff Training Centre for Deafblind Services (NUD), now the Danish branch of the Nordic Centre for Welfare and Social Issues, started cooperation with Estonia, Latvia and Lithuania. The cooperation began as a follow-up on a seminar in Riga in 1992, where it was decided that three of the Nordic countries should share knowledge; each with one of the Baltic states. Hereafter, cooperation was organized between the following countries:

- Estonia and Finland
- Latvia and Denmark
- Lithuania and Norway

On the background of resources and welfare conditions in the three countries, this cooperation was widely varied.

Staff services for the deafblind in Finland and Denmark gave support to Estonia in form of information on how to start classes for the deafblind at Helen School, a special school in Tallinn. As time grew by, Denmark pulled out and the cooperation with Finland continued with the exchange of deafblind people at summer camps and events which still exist.

In Latvia, staff services for the deafblind from Denmark travelled to quite a few institutions in order to identify people with deafblindness and give guidance to the pedagogical staff. The cooperation lasted only for a couple of years.

In Lithuania, with guidance from Skådalen School for the Deafblind in Norway, a school department for deafblind children was opened at the school for the blind in Vilnius. Skådalen has given guidance to this deafblind department until in 2009.

The above mentioned initiatives were taken by NUD. To begin with, the activities were also financed by NUD, but hereafter it was up to the Nordic institutions themselves to continue at their own cost.

Both Lithuania and Estonia have also in recent years received guidance in working with the deafblind and staff training for deafblind services from Hilton Perkins International in Boston. In the Nordic countries, there is many years'

tradition of strong professional cooperation on working with the deafblind. The following is an extract from the homepage of NVC (2010):

In the Nordic countries, there is a strong tradition of putting each human being's needs and wishes at the centre of an equal and full participation in social life. The Nordic Centre for Welfare and Social Issues – Staff Training for Deafblind Services contributes to reaching this goal through supplementary training of staff who work with deafblind people. The deafblind work in the Nordic countries – Iceland, Finland, Norway, Sweden and Denmark – has taken place for more than a hundred years. The first offers for congenitally deafblind school children came though from the middle of the sixties in many schools, while the work for those with acquired deafblindness was strengthened by an extension of the services at the beginning of the seventies.

Staff who worked with congenitally deafblind children in the Nordic countries had a great need for exchanging ideas with other colleagues. Since the group of service staff for the deafblind was small in each country, a united Nordic effort took place. The first meetings in order to exchange experiences were held at the beginning of the seventies and continued alternatively in the Nordic countries until the beginning of the eighties. The Nordic Staff Training Centre for Deafblind Services was established in 1981 on an experimental basis until NUD four years later was made a permanent centre placed in Dronninglund in the northern part of Jutland in Denmark. On January 1, 2009, NUD became a daughter institution of the Nordic Centre for Welfare and Social Issues.

Furthermore, it appears on the NVC homepage that cooperation with the Baltic states and northwestern Russia should be strengthened and that once more in 2008 a project on deafblindness was started:

The Nordic Council of Ministers supports the cooperation with the adjacent areas of the Nordic countries for mutual benefits, herewith the work in the Baltic states and the northwestern regions of Russia. Since 1992, the institution has cooperated with people with deafblindness, their next of kin and professionals in Estonia, Latvia and Lithuania. As of January 1, 2009, NVC's Department of Staff Training for Deafblind Services has hired a project worker for a one year position, established with the aim to start projects in the Baltic states, northwestern Russia and Kaliningrad.

The project was, with a considerable preliminary effort in 2008 and on basis of the above, started

as a one year project and ran from 01.01.09 until 08.01.10.

Agreements were established and carried into effect in the countries Estonia, Latvia and Lithuania and in the Russian region Kaliningrad, while an attempt for cooperation with the Russian region St. Petersburg was not successful.

The project came to an end in March 2010 with a course on deafblindness at NVC in Denmark with five participants from each of the three cooperating countries (Lithuania, Latvia and Estonia) and Kaliningrad.

The main aim of the project was to create knowledge and awareness of deafblindness in the three countries and Kaliningrad.

3. Culture and organization

Kaliningrad, Lithuania, Latvia and Estonia are widely different with regard to population, culture, organization and political structure. Therefore, it was important from the beginning to find out which context the project should take its starting point from in each country. Therefore, the cooperation in Estonia and Latvia was introduced by a clarifying visit, where I, in cooperation with information officers from the local offices of the Nordic Council of Ministers, met with key people who could inform me of the already existing work with deafblind people in the countries. During these meetings, strategies and plans were set for my projects in each of the countries and my work was focused on issues pointed out by the key persons' own needs and wishes. I believe this to have been a very important factor for the successful carrying through of the projects, in such good cooperation and with such good results in both countries.

In Kaliningrad, the leader of the Nordic Staff Training Centre for Deafblind Services (NUD) had already before my appointment participated in a preparatory meeting and we could already in October 2008 host a preliminary seminar of two days duration.

In Lithuania, where both Skådalen in Norway and Hilton Perkins International were involved, we had a shared clarifying meeting before I made arrangements for the project period.

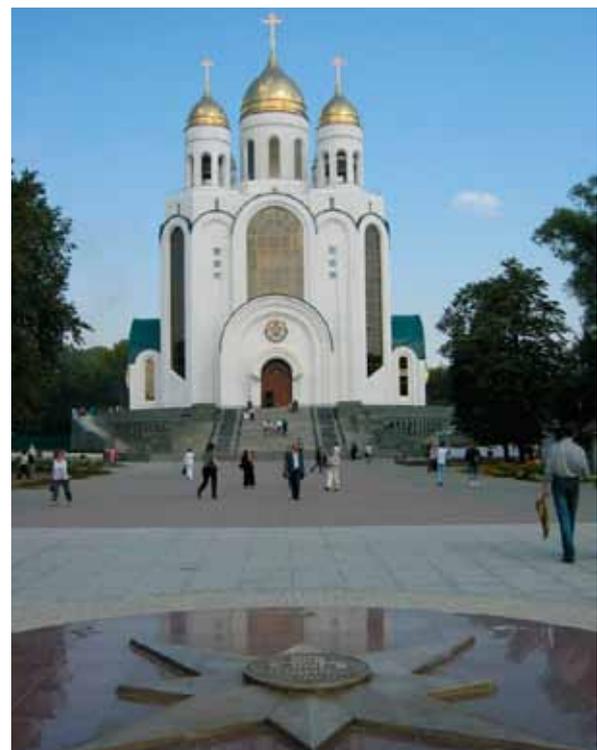
In the three countries and Kaliningrad, I received much support from the information officers from the local offices of the Nordic Council of Ministers, in order to establish contacts and to understand and act in societies which all are very different from the Nordic countries.

4. Cooperation and results in Kaliningrad

Kaliningrad was German until 1946 and after that a Soviet district with headquarters for the Soviet Baltic fleet until the disintegration of the Soviet Union in 1991. Kaliningrad is now a region of northwestern Russia which is separated from the rest of Russia by a coastline to the Baltic Sea and borders to Poland and Lithuania. Most of the inhabitants are only one generation old immigrants from the former Soviet Union and therefore there are very strong ties of national affiliation to the rest of Russia, where many of those engaged in active employment have received their education. Many disabled children get assessment and treatment in St. Petersburg or Moscow.

As a professional from a Nordic country, I experienced at the beginning a great deal of mistrust with regard to my use of methods used in the Nordic countries. Kaliningrad does not have any experience with people with deafblindness and had at the beginning of our cooperation no people who had been identified as being deafblind. The mistrust changed to some extent as time grew by and the professionals I met were better able to understand what deafblindness really is and especially when we were able to identify a child with CHARGE syndrome and with deafblindness as a result thereof.

Already in October 2009, a colleague of mine and me arranged a seminar on deafblindness in Kaliningrad for approximately 70 professionals. Hereafter, we made an agreement with key



people that the project should be used for detection and assessment of deafblindness. Therefore, I visited several kindergartens and schools with children with vision and hearing impairment. In these institutions, I made functional assessments of children who had been chosen by the staff.

At the beginning of the project period, I thought that Kaliningrad was such a small and limited area that it would be possible to detect and identify most of the children with deafblindness within the course of one year. It turned out to be a fairly difficult task to get permission to visit the big institutions for mentally disabled children; and schools for the deaf and blind only enroll children with the resources to reach far in the school system. Therefore, I did not meet many children with deafblindness in the project period. I met four to five children with minor combined vision and hearing impairment and one deafblind child with CHARGE syndrome.

I arranged one more seminar on children with minor combined vision and hearing impairment for relevant professionals.

Once we had found a deafblind child with CHARGE syndrome, it turned out that the staff in fact knew about a number of other similar children. However, this happened at a very late stage of the project period and therefore these professionals were invited to the final course in Denmark.

I visited Kaliningrad four times all in all at a duration of three to five days each.

5. Cooperation and results in Lithuania

Lithuania has a varied political history and the population has, as a result hereof, a marked mistrust of the political and public systems. This has even spread to internal mistrust between professionals. It is therefore common practice that professionals try to keep their knowledge to themselves and only reluctantly share it with others and there is mistrust to professionals within other professional fields. My experience was that pedagogical staff rather relied on foreign professionals than local professionals. This holds true both within their own subject as well as within other subjects. As an example, the pedagogical staff did not consider medical explanations made in Lithuania as valid, even though it was pretty obvious from prints of the patient's medical records, which examinations had taken place and which results had been found. Because of this, I experienced great trust as a foreign expert in Lithuania, but found it difficult to organize seminars, which were intended to spread knowledge to professionals outside of Vilnius.

Lithuania has a school department for congenitally deafblind children and guidance for other children in the country who are deafblind and blind with multi-sensory impairments. Leadership of the school department and the national guidance are attended to by one and the same person. The deafblind department has been in existence since the mid nineties and was started and is still led by a fiery soul who has extensive knowledge on deafblindness. All knowledge on deafblindness is concentrated in this one person, which I for one part find admirable, but also find very inconvenient as an organizational form.

The deafblind department is, apart from being a school department for deafblind people and multi-disabled blind people, also under an obligation to give guidance to parents and institutions with deafblind individuals throughout the country. The staff at the deafblind department does not, though, have the authority to assess and diagnose/identify deafblindness. This causes a great deal of problems in terms of giving guidance, since it often becomes a war of words in the institutions and schools about whether at all the child has deafblindness or not. This obviously causes great problems in terms of being able to give guidance on deafblindness and pedagogical methods concerning this particular disability.

I have therefore suggested to the representative from the Ministry of Education to find out who should make the official assessment and identification of deafblindness. I have also suggested the creation of a deafblind team with representatives from all of the special schools in the country, a team which should get the same education on deafblindness and competencies, in order to establish a shared development of the field. This will both spread knowledge on deafblindness to more people and provide a more official platform to give guidance from.

During the first visit, I met with the foreign experts from Norway and Boston and with leaders and staff from the Deaf School, Centre for the Blind, Department for the Deafblind, the Ministry of Education and the local office of the Nordic Council of Ministers. The meeting did not end with any useful strategies, so it was not until my next visit we reached agreement on the following:

- The arrangement of two seminars for professionals
- A visit to an institution for the mentally disabled with special focus on assessment and guidance
- A demonstration of how to make observa-

tions and an assessment of a child and of how to write an observation report and how to present it to parents and professionals

- An attempt to make a suggestion for a generally better organization of the work with people with deafblindness in Lithuania

During the project period, I also gave a little speech at a conference titled "Inclusion for All" and had a meeting with representatives from the Special Education Faculty at Siauliai University on education about deafblindness within a few branches of the Special Education Faculty.

I have visited Lithuania four times at a duration of three to five days each.

6. Cooperation and results in Latvia

Latvia became independent in 1990 and has since been through big changes. The country is though still marked by 20 years of political and economical instability. There are many fiery souls in Latvia who are ready to fight for development and improvements of social issues, but in 2009 (the project period), the reductions were so extensive all over in the social institutions that nothing could be started or implemented.

Detecting and identifying people with deafblindness also was a problem because of the very strict data protection laws which make it impossible for professionals to refer students from one institution to another. Professionals told me that they earlier on had been able to bypass these laws, but due to the latest restrictions, they were unable to do so any more.

Because of the above mentioned reasons, I decided, together with the key persons, to arrange a range of seminars on deafblindness. There was widespread interest and all in all approximately 190 people attended my seminars in Latvia.

During the period, I visited a blind school and a deaf school in Riga. I met a young deafblind boy and his mother, who earlier had received support and guidance from one of my colleagues in Denmark. I also visited the rehabilitation centre for the blind.

I have visited Latvia three times at a duration of four to six days.

7. Cooperation and results in Estonia

Since its independence in 1991, Estonia has quickly developed to a modern country with a relatively strong economy and Tallinn is a highly modern capital. The population compares itself culturally and intellectually to the Danes, and



therefore it is comparatively easy as a Dane to work in Estonia.

At Helen School in Tallinn, there is a department with deafblind people and multi-disabled blind people. Apart from the cooperation with Denmark and Finland, professionals from here have also received support from Hilton Perkins International, and they have in 2008-2009 run on an experimental basis an education of six modules on deafblindness at the University of Tartu. The education was aimed at professionals who work with multi-disabled blind people and deafblind students. Unfortunately, this education stopped again after one year because no one had the resources to make it permanent in the educational system.

During my first visit to Estonia, I could sense that there was knowledge about deafblindness and they had experience in cooperation between special schools. Many deafblind children were known by the system and new ones were detected early. However, professionals told me that they found it difficult to transform theory from their education on communication with people with deafblindness to good practice. Therefore, we agreed upon, during the introductory meeting, that I would take a round trip and visit all the special schools and choose a few children for the projects after the trip.

Thus, my project period in Estonia resulted in projects with four children spread to three special schools in various places in the country.

Helen School in Tallinn:

- An 11-year old deafblind multi-disabled boy. Network: Class teacher and the boy's mother
- A 16-year old boy with Usher syndrome (acquired deafblindness). Network: two teachers, the boy's mother and the boy himself

Emajõe School in Tartu:

- An 8-year old girl. Main diagnosis unknown. Totally blind and slightly hearing impaired. Network: the teachers in the girl's class.

Porkuni School in the middle of the country:

- A 12-year old boy with a slight hearing impairment. Main diagnosis unknown. Network: the teachers. I met the boy's mother once.

I visited each child four times and during each visit I attended the lessons of each child, worked with the child, videotaped the activities of the child, held meetings with the network and educated the professionals.

During my last visit to Estonia, I held a two-day seminar for professionals from all over the country. At the seminar I taught about social interaction and communication with people with deafblindness and used the four children from the project as case-stories.

During one of my visits to Estonia, I was followed by a TV-crew from one of the largest TV-channels in Estonia. This resulted in a 20-minutes program on deafblind children and on my work in Estonia. The program was seen by approximately 300,000 people.

On top of that, I was interviewed and photographed by a journalist and a photographer for an article to a monthly journal for families. During the project period, I visited Estonia six times at a duration of three to six days.

8. Course in Denmark

To conclude the one year project, I arranged a course at the Danish branch of the Nordic Centre for Welfare and Social Issues with five participants from each of the countries involved in the project.

The aim of the course was:

- To create networks and sharing of knowledge in the countries and between the countries
- To enable the participants to know even more about deafblindness

- To show the participants how work is done in Nordic institutions for the deafblind
- To give the participants an opportunity to meet other Nordic experts on deafblindness
- To give the participants an increased knowledge of the work of NVC Denmark

The course was mainly financed by funds from the offices of the Nordic Council of Ministers in the involved countries. The rest was financed from the budget that was allocated to the project by NUD in 2008.

At the course, there were lectures on the progress of the project and the results in the respective countries, deafblind pedagogy, communication with the deafblind, teamwork, video analysis, work culture in the Nordic countries, institutional visits and so on.

The course was a great success and the participants were active during discussions and have subsequently reported great benefits from the course.

See appendix for the course program

9. Recommendations

My work in each of the countries has, as far as possible, been based on the status of the political and economical systems, as well as the status of the professional staff and I have all the time tried to adjust in accordance with wishes from the participants.

Since the project lasted one year, it is from now on up to the professionals to formulate their wishes for a continuation of the cooperation and to seek continued financial support.

9.1. Kaliningrad

I think it should still be possible to detect most of the region's deafblind children by visiting the big institutions for children with physical and mental disabilities and by making assessments of blind and visually impaired children with additional disabilities. This would also apply to institutions for adults in Kaliningrad.

The five professionals who participated in the course in Denmark do have knowledge of a couple of children with CHARGE syndrome, one also might check for deafblindness, since people with CHARGE often are deafblind or do suffer from a high degree of a combined vision and hearing impairment.

The professionals in Kaliningrad told me that there is considerable knowledge on deafblind-



ness in Moscow and St. Petersburg, so I would recommend cooperation between Kaliningrad and either professionals in the Nordic countries or in Russia, in order to detect and assess people with deafblindness and in order to develop a professional field of specialists on people with deafblindness in Kaliningrad. During the course of 2008-09, I have been in contact with approximately 80-100 professionals. These people now have a firsthand knowledge of deafblindness, which they can now build on.

From here, I would recommend a continued cooperation between Kaliningrad, NVC and the Nordic Council of Ministers for detection and assessment of people with deafblindness in Kaliningrad.

9.2. Lithuania

I would like to recommend the establishment of a national team on deafblindness in Lithuania. I have suggested earlier that the team should consist of professionals from special schools throughout the country, the leader of the deafblind department in Vilnius, one person from an assessment institution which can assess, diagnose/identify deafblindness and one official from the Ministry of Education.

If such an organizational form will be established, the field of deafblindness in Lithuania will have, if possible, an even greater need for support from Nordic experts than they have had up to now, since the whole team will need knowledge on deafblindness, assessment, development of communication with people with deafblindness, video analysis and so on.

Skådalen in Oslo has for a number of years been in charge of and paid for education and guidance to the deafblind department in Vilnius. This has helped develop both knowledge and good practice in the department. If a formal assessment procedure and a deafblind team will be established, support from Nordic experts will be needed even more in years to come.

I would like to recommend to the field of deafblindness in Lithuania that they formalize the assessment of deafblindness, establish a deafblind team and seek continued financing from European funds for support and guidance from the Nordic countries. I would also like to recommend Skådalen that they continue their support to this new organizational form, e.g. because of their experiences from working in Lithuania and because they do have the necessary prerequisites to both guide the practitioners and to teach special pedagogic staff at special pedagogic faculties at university level.

9.3. Latvia

In 2009, Latvia was extremely hard hit by the economical world crisis; there were job dismissals and wage reductions on the agenda and nothing new was created. Therefore, it is not realistic at this point of time to start new initiatives on deafblindness in Latvia. Yet, I have met several fiery souls who are waiting for this to happen, e.g. the leader of the blind school in Riga.

My recommendation with regard to Latvia is therefore to wait and to comply with applications for new initiatives from there when they are ready for it.

9.4. Estonia

Within 15-20 years, Estonia has established quite a strong field of deafblindness expertise, and does therefore not need any further support for starting up and establishment. At the present moment, Estonia has need for sparring with equal partners from professional institutions on deafblindness in other countries. Even though Estonia became a member of the EU in 2004 and has developed dramatically in terms of economy ever since, they are still not at the level of the rest of Europe and cannot afford, within the social sector, to participate in courses, work seminars and conferences abroad.

From here, I would recommend that NVC and the Nordic Council of Ministers give support to Estonia's wish for increased cooperation with the field of deafblindness in the Nordic countries.

10. Nordic benefits and the cooperation with the adjacent areas of the Nordic countries

During the project period, it has been of utmost importance for a successful result that I have been able to cooperate with the very competent information officers at the offices of the Nordic Council of Ministers in Kaliningrad, Riga, Vilnius and Tallinn. They have all contributed extensively to the project and have during the whole process been helpful in all aspects with regard to contacts, practical arrangements, interpreters and interpretation, written material, translations, sparring, support and so on.

Nordic colleagues have during the whole process been helpful in terms of sharing knowledge and experience from earlier projects and by being sparring partners on my work.

During my first visits to the three Baltic countries, I constantly ran into people who could recall earlier meetings with Nordic colleagues, and overall I could see results from their support and guidance

with regard to the present work regarding people with deafblindness in these countries.

With their high professional standards and the knowledge that has been gathered and developed on deafblindness in the Nordic countries within the past 30 years, the Nordic Centre for Welfare and Social Issues, and Nordic colleagues, have a lot to share with the adjacent areas of the Nordic countries. As a world leader on a relational approach to the development of social interaction and communication with the deafblind, we are obliged to pass this knowledge on to our neighbouring countries.

The reason for my great success in this project, especially in the three Baltic countries, is that we are able to add this dimension to the already existing work, which due to the cultural likenesses will fit to the work done at schools and institutions as well as to the pedagogical thinking



already in function at the pedagogical educational institutions of these countries. Therefore, it is my hope that my work will be continued in each of the countries, as soon as these are ready to formulate their wishes for further projects.

11. Summary and conclusions

The NVC project of spreading knowledge and awareness on deafblindness in northwestern Russia and the three Baltic states has now come to an end.

This report describes the organization of the project and the results in each of the countries. There are also recommendations for further work, which, with advantage, could be done while a lot of people still have a fresh memory of hearing something or something new on deafblindness.

The aim of the project was that many people in each country should gain an awareness and knowledge of deafblindness. If I should give a guess, then I think I have contributed with knowledge on deafblindness to more than 300,000 people through TV and directly to approximately 100 professionals in Estonia, 200 in Latvia, 100 in Lithuania and 100 in Kaliningrad. This means that the project has contributed to increased awareness of deafblindness among approximately 500 professionals and 300,000 laymen. Subsequently, I think I have revealed a growing need in all the countries for more specific knowledge on deafblindness. In Lithuania and Estonia, where people already work goal-oriented on deafblindness, I have contributed with additional knowledge as well as being able to reach professionals who had not been aware of deafblindness as a distinct disability earlier.

The course in Denmark has given five professionals from each country a possibility to see and hear how we work with deafblind people in the Nordic countries and provided them with new knowledge, which I hope they will bring back home and use in their daily work. On top of that, each country now has a small team of five people, who are knowledgeable on deafblindness and who have had time to discuss and get acquainted to such an extent that they can contact each other in the future. They have met professionals from their neighbouring countries, which they will also be able to contact in the future.

Finally, I have been in contact with government departments and educational institutions in all of the countries, which thereby also have become aware of the fact that deafblindness is a distinct disability, and that people with deafblindness have distinct needs.

As mentioned in the chapter Recommendations, all the countries need more follow-up and this would of course be appropriate now, when the supplied knowledge can still be remembered and used. I would especially like to mention Lithuania, which is considering the suggested reorganization and Kaliningrad, which with continued support could carry out identification work in the whole region with comparatively little help and thus find the people with deafblindness in the country.

No evaluation has taken place of the project apart from the response we have received from the participants at the course in Denmark and from the offices of the Nordic Council of Ministers in the respective countries. We have only received positive feedback from both places.



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