



Foundation to further the quality of life - comprising social inclusion – of persons with a disability

ANNUAL REPORT 2010

1. INTRODUCTION

SOFT Tulip Foundation was established in 1991 by Dutch health care experts who were moved by the fate of disabled children in Hungary. They wanted to help to improve their health care as well as their living conditions. Together with Hungarian colleagues they established the SOFT Alapítvány (Foundation) in Debrecen. (SOFT being the acronym of 'help, protect your disabled fellow human being' in Hungarian). Simultaneously in the Netherlands SOFT Tulip has been founded.

SOFT Tulip is nowadays a network organization of care providers in the Netherlands which aims at furthering the quality of life – including social inclusion – of persons abroad with a disability in accordance with the United Nations' Convention on the Rights of Persons with Disabilities. Rooted in basic values characteristic of Dutch culture such as freedom, equality, and solidarity, SOFT Tulip assists its partners abroad to further the quality of life of persons with a disability in their own country. Doing this, it draws upon the insight, knowledge, and experience that have been accumulated within a strong and vibrant civil society encompassing the development of helping networks, the advocacy of the interests of persons with disabilities as well as the stimulating of policy changes necessary to develop an inclusive society. It draws also upon the insight, knowledge, and experience gathered within its network of care providing organizations in the Netherlands. Simultaneously it learns with and from its partners to find solutions for the challenges due partly to globalization and partly to local problems. In other words, SOFT Tulip became a knowledge organization whose scope in terms of geography is not limited anymore to Central and Eastern Europe, whereas its ultimate target groups are persons with disabilities regardless their age, gender, religion, nationality, ethnicity or the kind of disability.

2. ADMINISTRATIVE MATTERS

2.1 Director

In 2010 Mr. F.J.H.M. (Eric) Bloemkolk was the part-time director and directed the foundation's daily business, reporting to the executive committee. With the Socires Foundation a cost sharing agreement was signed, covering salary and administrative costs.

2.2 Executive Committee

The executive committee consists of the president, vice-president, secretary, treasurer and another board member. In the year under review the executive committee gathered 6 times.



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2.3 Board

The board held 2 plenary meetings. At the beginning of the year under review its composition was as follows:

Mr. E.W.C.M. Damen
Mr. W. de Gooijer (EC member)
Mr. J.G.A. van Hoek
Prof. Dr. J. Katus (president)
Mr. L.J.M.. Kenter
Dr. H.R.T. Kröber
Mr. S. J. Vegter MBA (treasurer)
Mr. J. Verrijck (vice-president)
Mr. D. C. van de Velde (secretary)
Mr. J.A. Welling

The board learned with sadness that its former member Mr. Riekus Feijen has passed away.

During the year under review the Lelie Zorg Groep has joined SOFT Tulip. As of July 2010 Mr. Johan van der Ham, is representing it in the board of SOFT Tulip.

3. POLICY MATTERS

3.1 Relationship with the Zorgcoöperatie Nederland

As successor of De Open Ankh, and in accordance with earlier agreements, as of 2010 Zorgcoöperatie Nedeland (ZCN) was supposed to pay SOFT Tulip during five successive years an annual subsidy of € 50,000. However, due to its own internal affairs, ZCN turned out not be inclined to meet its obligations. In the course of the year under review intensive negotiations with ZCN took place, ending with a compromise enabling SOFT Tulip financially to continue its activities. Simultaneously, the within SOFT Tulip's framework cooperating care providing organisations decided to adapt their annual contributions in order to compensate the threatening budget deficit caused by ZCN

3.2 Modification of the regulations

The mission and vision of SOFT Tulip as described above in the *Introduction* resulted in 2010 in the new statutes of SOFT Tulip. From 2010 on SOFT Tulip is open towards cooperation in all other countries in the world where there is need for the quality services and involvement of our specialists. The office of SOFT Tulip was transferred to The Hague, sharing the premises with the Socires Foundation. For the review of our finances the accountancy firm Koeleman was contracted. There are seven board members formally representing a care providing organization, and there are three board members owing to personal competences. In the beginning of 2010 the following care providing organizations are represented in the board of the foundation: Cor-



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daan (Amsterdam), De Trappenberg (Huizen), Pameijer (Rotterdam), Royal Visio (Huizen), Steinmetz/De Compaan (Rijswijk), Talant (Heerenveen) and, Zuidwester (Middelharnis). The total number of employees of these organizations is about 10,000 and their total annual budget amounts to approximately € 900 million. In the year under review an active search was started to attract other care providers to join SOFT Tulip, foreseen for the next year.

3.3 Policy guidelines

In view of the reconsidered mission and vision of the foundation the board assessed guidelines for future policy. Taking into account that the quality of life of people with disabilities in the countries where SOFT Tulip is and will be active depends on a relatively high measure on policies of local and national governments, its efforts should aim simultaneously at influencing government policies and improving health care services. This approach implies the building of multi-stakeholder networks. The foundation aims at the development and implementation of twinning programs. This policy is dictated partly by the size and the gravity of the problems to be tackled, and partly by the limitedness of SOFT Tulip's means and possibilities. Apart from the synergetic aspects of co-operation, strategic partners in the Netherlands as well as abroad are also necessary because of the world wide economic and financial crisis that goes with severe cuts in budgets of user organisations, providers, donors and authorities alike. The board and its director put a lot of emphasis in establishing strategic partnerships with consultancy firms like Span Consultancy, donor organisations like Skanfund, Cordaid, Liliane Fund, Hofstee Foundation and alike. SOFT Tulip also participated in activities of the Better Care Network, Dutch Coalition on Disabilities in Development (DCDD) and the Dutch Coalition for Inclusion.

3.4 Communication

In the year under review the renewed website www.softtulip.nl became an important tool for the communication about our activities.

4. MEMBERSHIPS

4.1 International SOFT Federation

SOFT Tulip is a founding member of the International SOFT Federation (ISF). This umbrella NGO came into being after the successful completion of a Dutch-Hungarian-Romanian project that has been designed by SOFT Tulip and the SOFT Alapítvány, its Hungarian sister foundation, furthermore implemented in co-operation with Caritas Satu Mare, Romania with the financial support of the European Union. In 2001 twenty-eight NGOs from Hungary, the Netherlands, Romania and Ukraine issued a Declaration of Intent envisaging the establishment of a federation of NGOs working for or with disabled children and young adults. In the course of time its target groups became persons with a disability and its mission is furthering the quality of life of people with a disability in accordance with the United Nations' Convention on the Rights of Persons with Disabilities. ISF works under Hungarian law and has an international board.

During the year under review SOFT Tulip representative in this board was its president who in 2001 has been elected also as the president of the international federation. At the end of the year under review, the number of ISF organization-members amounted to 39.



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4.2 European Association of Service Providers for Persons with Disabilities

SOFT Tulip is, furthermore, member of the European Association of Service Providers for Persons with Disabilities (EASPD). This umbrella NGO represents over 8,000 social service provider organisations across Europe and across disability. The main objective of EASPD, based on the UN Convention on the Rights of Persons with Disabilities, is to promote the equalisation of opportunities for people with disabilities through effective and high quality service systems. EASPD members believe in interdependence and partnership of user organisations, providers and authorities at all levels to tackle the challenges ahead.

In 2010 SOFT Tulip representative in EASPD was Mr. Willem de Gooijer. In this year he represented SOFT Tulip at the annual conference and General Assembly held in Skopje, capital of Macedonia.

Under the title “Community Living: Current realities, future challenges”, the EASPD held a conference with high levelled keynote speakers and workshops which stimulated lively discussions and exchanging of experiences.

SOFT Tulip maintains good and productive contact with the executive secretariat and staff of the EASPD.

5. OTHER ACTIVITIES

5.1 The 2010 SOFT Tulip Meeting in the Netherlands

The care providing organizations working together within the framework of the foundation represent an impressive reservoir of knowledge and experience, but the board realizes that all over the country there is much more knowledge and experience available. Therefore, it attaches great value to communication and cooperation with other Dutch organizations. In view to this, it holds annually SOFT Tulip Meetings in order to stimulate the exchange of knowledge and information between relevant health care organizations in the Netherlands.

The 2010 SOFT Tulip Meeting was the fourth of such gatherings and took place on February the 4th. It has been attended by approximately hundred persons representing several organizations from all over the country. Mr. Caspar Veldkamp, head of the Eastern Europe department and the Matra program presented the new policies of the Dutch government towards Eastern Europe and on the Matra program. From the side of the foundation a progress report has been presented by Mrs. Lesya Kalandyak, the Ukraine coordinator and the director of SOFT Tulip, Mr. Eric Bloemkolk on the Matra project ‘Improving the quality of life and standards of services for children with disabilities in Ukraine’ (see 5.7 underneath), whereas board president József Katus presented the latest developments in the SOFT Tulip organisation.

5.2 Activities related to the Republic of Moldova

Following the exchange of information with the Dutch foundation Janivo concerning common activities and strategies in relation with the Moldovan NGO ACASA, in the year under review SOFT Tulip has worked out with ACASA a proposal for the Dutch government’s Matra program, focusing on training of staff in NGO day care centers for disabled children and to strengthen their network in the Republic of Moldova. On behalf of SOFT Tulip, Mr. Jan Broeders together with director Mr. Eric Bloemkolk visited Moldova to prepare with ACASA’s network the proposal.



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Unfortunately towards the end of the year it became clear that due to the budget restraints of the Matra program, no funding opportunities existed anymore for this program.

Simultaneously and with the interference from board member David van de Velde and expert Mr. Jan Broeders the creation of the first day care center for severely disabled children 'Pasarea Albastra' (Blue Bird) in Hencesti was supported.

5.3 Activities related to Surinam

On the basis of the visit to Surinam in 2009 SOFT Tulip and the VPSI decided to work out a plan for further cooperation. In 2010 this plan has been elaborated through e-mail contact to be presented to the UTSN, a twinning fund for NGOs from Surinam and the Netherlands. Unfortunately also this fund was financially exhausted in 2010. VPSI and SOFT Tulip decided to present the proposal to another donor organisation in the coming year.

5.4 Activities related to Hungary

5.4.1 Due, among other things, to the serious illness of the dean and to the outcomes of the general elections held in 2010, progress of the cooperation regarding the development of disability studies at the Faculty of Adult Education and Human Resources Development of the University of Pécs met with difficulties. As far as the elections are concerned, political authorities as well as senior civil servants of the previous government have been replaced by adherents of the new ruling party. As a consequence, promising contacts relative to the project with the Ministry of Social Affairs and Labour ceased to exist.

5.4.2 On the other hand, progress has been made at the University of Debrecen. At the initiative of the SOFT Tulip representative in the board of the International SOFT Federation (ISF), an Educational Centre of Disability Studies in Central and Eastern Europe has been established at the University's Department of Physical Medicine and Rehabilitation, headed by Prof. Dr. Zsuzsanna Vekerdy. The Centre's mission is to contribute to the development and implementation in the region of innovative programmes answering educational needs related to disability issues in accordance with the working guidelines of the International Society for Disability Studies.

5.4.3 As another manifestation of the cooperation with Debrecen University should be mentioned the CARP workshop held with the participation of Dutch experts by Dr. János Kollár in the Netherlands. Dr. Kollár has developed a program for computer assisted rehabilitation and the workshop has been set up in order to discuss his methods. The workshop was successful, and the program is considered as mature for diffusion.

5.4.4 During the year under review president Erzsébet Szeekers of the Foundation for Equal Opportunities (FEQO) visited the Netherlands, meeting president József Katus and secretary Mr. David van de Velde. Mrs Szekeres is member of the board of ISF and an internationally recognized social entrepreneur. The purpose of her visit was development of touristic travels for Hungarian people with disabilities. In this context particular attention has been paid to the barrier-free ship 'Prins Willem Alexander'. Mr. Van de Velde was involved in the realization of this ship and has experience with its utilization.



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5.4.5 Earlier in 2010, SOFT Tulip's president and secretary have together paid a visit to FEQO. During this visit possibilities have been discussed of the development and implementation of international training and education programs for health professionals and volunteers. In terms of accommodation and logistics, FEQO's seat in Csömör is highly suited for the purpose.

5.5 Activities related to Serbia

On invitation of the Dutch Skan foundation and their Serbian partner organisation BCIF, SOFT Tulip participated in an EU funded training program for Serbian NGOs and representatives from the Serbian government. The project enhanced the process of capacity building of NGOs, to provide quality services for disabled people and their families, to network them and to create an open dialogue with national institutions regarding NGO participation in the social welfare system in Serbia, based on the experiences and expertise from the Netherlands. At the same time, the project enabled representatives from the relevant institutions and associations of professionals to get acquainted with the examples and expertise from the Netherlands. SOFT Tulip expert, Hans van der Wielen together with the director of SOFT Tulip and the Serbian counterparts a tailor made 4 day training program in Serbia was developed and given in the period of September – November. In December a visit of a Serbian delegation to the SOFT Tulip network in the Netherlands was organised. The program was executed with such a positive feedback from the Serbian participants that it was agreed upon to present a new proposal for cooperation to the EU in the coming year.

5.6 Activities related to Ukraine

5.6.1 The cooperation between SOFT Tulip, Socires, the Dutch Parents' Organisations Helping Hands and two local Ukraine parents' groups in Lviv (connected with Dzherelo Children's Rehabilitation Centre) and in Uzhgorod (connected with Doroga Zhyttya Rehabilitation Centre) has resulted in two well functioning formal parents' organisations. In this context successful workshops were given by Helping Hands, facilitated by SOFT Tulip in March 15 – 21 and September 21 – October 2 on the themes of 'strengthening parents' organisations' and 'sexual education for children with disabilities'. The workshop on sexual education was given in Lviv to parents *and* professionals working with disabled children from Uzhgorod and Lviv. The experiences of the two parents' organisations were presented in October in Kiev at the meeting of a national platform of parents' organizations where more than 100 parents participated, organized by our partner organisation National Assembly of Disabled of Ukraine, NADU.

5.6.2 Positive developments in the Matra Ukraine project

2010 was a very successful year, with better results than expected in all areas. New spin offs were generated and the cooperation with the new government turned out to be productive. In February a delegation from Ukraine being the team of trainers from the Dzherelo Centre visited the SOFT Tulip network to receive trainings and to visit care centres in the field of Early Intervention. The members were: Mrs. Yaroslava Klymovets, Mrs. Tetyana Mishchuk, Mrs. Nataliia



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Pomirko, (translator), Mrs. Oksana Duma, Mrs. Maryna Hlukhotska, Mrs. Lesya Kalandyak and Mr. Yevheniy Sukovsky.

In July another early Intervention delegation visited the Netherlands to improve the cooperation between Ukraine civil society organizations and the Ukraine government in the reform of the Early Intervention system for the disabled children and their families in that country. The delegation was comprised of Mrs Valentyna Zaleska (First Deputy of the Head of the Department of Maternity and Childhood of Ministry of Health of Ukraine), Mrs. Anna Kukuruza (Director Institute of Early Intervention in Charkiv), Mrs. Lesya Kalandyak (Physiotherapist and Ukraine coordinator of the Matra project) and Mrs. Nataliia Skripka (Executive Director of National Assembly for people with disabilities in Ukraine). The delegation focused on the new policies and practices on Early Intervention for children with disabilities and their families in the Netherlands and shared experiences, good practices and policies with the Pameijer Foundation in Rotterdam; Steinmetz/de Compaan in Rijswijk/The Hague; Mr. Hans van der Wielen, trainer for the Ukraine Early Intervention Network, the Ministries of VWS (Health, Care and Sports), Mr. Floris de Boer, and of Youth and Family, Mrs. Susan Pottering; the National Network of Parents of Physically Disabled Children (BOSK) and the European Network on Early Intervention (Eurlayid); and with Mrs. Susan Holtrop, national coordinator of the VVI (Early, Constant and Integral) program in the Netherlands.

In order to secure the sustainability of the 'train the trainer' program for the improvement of the quality of services in internats for disabled children, the Dzherelo team of trainers in Lviv was extended with two more members. As a spin of the program, the Dutch 'Hogeschool Avans' provided an additional training program for the Dzherelo centre in Lviv.

The trainings in internats for disabled children improved significantly the capacities and attitudes of care practitioners, and stimulated the involved directors and doctors of the internats to make new changes, which again had a positive impact on the quality of life of the concerned children. These clear results helped to convince the Ministry of Social Policies to jointly embark in the planning and preparation of trainings in all Ukrainian internats (for level 1, 2, 3 and 4; about 55 in total).

The National Association of Physiotherapists has increased its membership and the Board members received trainings on the issues of lobby and advocacy. In 2011, the Association will become official member of the World Confederation of Physiotherapists.

The lobby and advocacy strategy focussed on the government resulted in an intensive cooperation between the Ukraine government, the partner organization NADU and the Ukrainian coordinator of the Matra program (Mrs. Lesya Kalandyak).

The impressive results of the feeding program (not funded through Matra but an essential part of our program) led to the public and political recognition of the malnutrition problem in all state run social services, stimulating the cooperation between the ministries of Health and Social Affairs, with the support of DSM expertise and in cooperation with UNICEF.

The SOFT Tulip partner NADU strengthened their role as strategic dialogue partner for the Ukraine government in all policy fields concerning the rights of people with disabilities. The ratification of the UN Convention for the Rights of persons with Disabilities was highly stimulated by NADU and the results of the Matra program.

The results of the program have been described by Mr. Eric Bloemkolk in an article called '*Co-operating for cohesion in Ukraine – learning from the reforms of a state run system for handicapped children*' which was published in the magazine of Life Long Learning in Europe.



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In the Ukraine, senior physiotherapist at Dzherelo and coordinator of the Matra program Lesya Kalandyak was elected by the public to receive the prestigious 'Golden Heart' award 2010 from a national and well known 'women magazine'.

The Ukraine embassy in the Netherlands honoured SOFT Tulip with the title 'Friend of the embassy of Ukraine'.

5.6.3 New initiatives

The established and fluent relationships with the Lviv Oblast and the Carpathian Oblast representatives of the Ministry of Social Policy have led to the exploration of new fields of cooperation: the care for the elderly and the reform of a so called 'psycho neurological institute' near Uzhgorod, which houses 320 men in a former concentration camp from World War II.

From 30 September till the 2nd October a delegation from SOFT Tulip, the Lelie Care Group and the Amaris Care Group visited Lviv to explore the needs for and possibilities of cooperation in the field of improving services for elderly people. Participants were Mr. Johan van der Ham, President of the Board Lelie Care Group, Mr. Arie Kars, Director of Care Group Rijnmond (Lelie Care Group), Mr. Jan den Ouden, President of the Board Amaris Care group and Mr. Eric Bloemkolk, Director SOFT Tulip. The home care program of Caritas – Lviv and in Brody was visited, as well as a big care institute for the elderly from the Ministry of Social Policy. With both Caritas as with the representatives from the Ministry further cooperation was agreed upon, through trainings and support on lobby and advocacy; on formulation of policies for and quality standards of services for the elderly; on rehabilitation services for the elderly (stroke, spinal cord injury and fractures) with as possible partners Caritas, Lviv Association for Physical Rehabilitation Specialists and Dzherelo Children's' Rehabilitation Centre, the university of Lviv and the state run Rehabilitation Centre of Lviv. Other specific goals are the stimulation of day activities; to improve the management of geriatric institutions and on working with palliative patients.

Also in October a visit was made with Dr. Erik Hoencamp from the Paranassia Bavo Group and Mrs. Ciska Goedhart from the Global Initiative on Psychiatry to Uzghorod in the Carpathian region (Oblast) of Ukraine. Our partner organisation 'the Path of Life Centre' organised a visit to a psycho neurological institute in Turja Remeta where 320 male patients with psychiatric problems and mental disabilities live in difficult circumstances. With the Head of the Regional Department of the Ministry of Social Policy. Mr. Viktor Matsola, the Deputy-Head, Mr. Vjachslav Mykulets and Mrs. Iryna Roshkovych vice director of the Path of Life Center, agreements were made for cooperation to improve the quality of care in this institute.