

Cooperation for cohesion in Ukraine

- learning from the reforms of a state run system for handicapped children

Ukraine is on the path towards reforming its care provision for handicapped children. Emergent Ukrainian civil society organizations have ushered in change, cooperating with international NGOs and governmental bodies to raise awareness of the inhumane situation in Ukrainian state run internats for disabled children. This article documents this process and its best practices of changing a policy of marginalisation.

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DISABILITY IN UKRAINE: THE BACKGROUND

Ukraine, a former Soviet Union republic that became an independent state in August 1991, inherited a Soviet public care system which strongly favoured placing handicapped people to remote and isolated institutions. Handicapped children and adults were considered to be of little value for the society. A rigid, purely medical assessment screened such children out giving them a legal label of 'disabled' and prevented them from entering mainstream nurseries and schools. Parents were told that the best thing to do was to entrust their child to the state run 'internats', where they would receive presumably proper specialised care. In Ukraine special internats were created for boys and girls depending on the severity of their condition. Level 1 and 2 internats were for children with mild mental and or physical disabilities who were labelled as 'having perspective' – a perspective for some participation in society - and level 3 and 4 internats existed for those who were considered as 'severely' handicapped and 'without perspective'.

The public care system established during the Soviet times is still prevalent in Ukraine, and the consequential institutionalisation of children accompanied by complete social exclusion is in essence a continuation of Soviet time policies concerning the disabled. Currently in Ukraine out of about 10 million children approximately 177,600 have disabilities. From this group of disabled children more than 70,000 live in 55 state-run institutions, the so-called internats, according to statistics from the Ministry of Social Policy and Labour (2009). There are 23 level 3–4 internats housing approximately 3,000 children of ages 4 to 18. Although the institutional care system in Ukraine has been going through reforms for the past 9 years and some positive results have been achieved (emergence of foster families, growing number of adop-

tions), disabled children reared in the institutions have only recently become the focus of attention of the Ukrainian Ministry of Social Policies and Labour in the process of this reform.

Until now, adequate services, rehabilitation programs and skilled professionals who can provide disabled children with the services and support for social integration and a life in dignity and good health have been insufficient and in many places even lacking. By and large, disabled people are often subject to stigmatization, have no access to schools or workplaces, and often end up living in institutions (internats) or being dependent on other family members and the community for physical, social, and economic support. Due to general poverty and the lack of social capital, combating social exclusion is extremely difficult. The state's expenditures on public health, education and other social welfare programs are well below the average European level.

LOCAL CIVIL SOCIETY ACTORS EMERGE

Throughout the last century, writers like Hanifan (1916 and 1920) and Putnam (2000) defined social capital as the capacity of a group, community or society to work together, to satisfy their social needs and to improve living conditions. The community benefits from the cooperation of the individuals and the individuals benefit from this cooperation, finding sympathy from their fellow community members.

During communist rule in the Soviet block countries, expressions of civil society were seen as a threat to the state, which claimed to deliver all necessary services for the people. Civil society organizations and their leaders were severely repressed and even eradicated.

Former President of the Czech Republic president Václav Havel (1999) stated the following on this subject:

While a totalitarian system of the communist type could now and then

coexist with private ownership, and sometimes even with private enterprise, it could, as a matter of principle, never coexist with a developed civil society. Genuine civil society is the truest fundamental of democracy, and totalitarian rule can never, by definition, be reconciled with that. It was therefore no coincidence that one of the most intense and possibly the most fateful attack that accompanied the installation of communist power was an attack on civil society. The freedom of speech that had been suppressed by communism overnight could, forty-one years later, be restored overnight as well. It was also possible to rapidly abolish the constitutional provisions concerning the leading role of the Communist Party, to establish other parties and to hold free elections. We even succeeded rather quickly in transferring the greater part of our nationalized economy into the hands of concrete owners.

In the realm of civil society, things are much more complicated; its restoration is a task that will take years. The reason is self-evident: civil society is an intricately structured, very fragile, sometimes even slightly mysterious organism that grew for decades, if not centuries, out of a natural development, reflecting the continuous evolution of the human mind and morality, the degree of societal knowledge and self-knowledge, and a certain type of civic awareness and self-confidence. After so many years of virtual non-existence, civil society, therefore, cannot be restored by any single act from above, such as a law, a directive or a decision of the political leadership. The only possibility is to patiently build an environment favourable to its advancement and to strengthen those characteristics of societal spirit that promote such advancement.

Social cohesion, as a crucial aspect of the restoration of the civil society and strengthening of the societal spirit, as described by Havel, results from the process of people working together in an organized way solving societal problems through cooperation and creating non-commercial public services, run by civil society organizations. Indeed, by working together for the improvement of living conditions, individual people strengthen their mutual ties and at the same time resolve concrete problems on such issues as, for instance, care for the handicapped or education.

In 1991, civil society - especially parents' organizations - started to emerge in Ukraine, creating services for handicapped children. As has been explained, previously, due to the lack of alternative services for the disabled children, parents were forced either to send their handicapped children to a closed state run institution, or to keep them at home and take full responsibility for their care and education. Nowadays some parents - although still a very limited number of them - can bring their handicapped children to day care centres run by civil society organizations. The Dzherelo Children's Rehabilitation Centre in Lviv and the Path of Life Rehabilitation Centre in Uzhgorod serve as excellent examples of such civil society organizations which emerged as a result of an effort of parents of disabled children to solve their problems through cooperation and establishment of a non-governmental public service organization. Because of a lack of financial support for these non-governmental services from the governmental bodies, only a few of these parents' initiatives manage to survive and the state run internat system is still in place.

THE START OF THE PROCESS OF REFORM: SMALL PILOTS

In 2006, a senior physiotherapist from Dzherelo Children's Rehabilitation Centre, Mrs. O. Kalandyak visited a

level 3-4 internat to provide some of the children with rehabilitation services. For her it was the first visit to such an internat, and she was shocked by its conditions and by the situation of the children reared there. She encountered severely malnourished, mostly bedridden children who spent their lives looking at the ceiling. Some of the children were even tied up to their beds, whereas others were crawling over the floor. No one was being offered any form of day activity at all. Mrs. Kalandyak immediately organised a group of people which included representatives from the Ministry of Social Policy and Labour, a paediatrician from the Dzherelo Centre, local politicians and church and civil society representatives to visit the internat, to examine the children, to discuss their problems, and to search for solutions. This was the beginning of a long, complex, sometimes exhausting and frustrating, but even more so a very fruitful process of mobilizing and strengthening civil society and its cooperation with the government and other stakeholders like churches, private companies, international organizations and politicians.

With the help from a local Roman Catholic priest, a therapeutic feeding program was immediately started to provide help to 10 severely malnourished children. The North American paediatrician and nutrition expert Jonathan M. Spector, M.D, from the Harvard School of Public Health was invited to examine the children in two 3-4 level internats. The findings in his report were compelling:

As a paediatrician with formal training in public health and extensive experience working with malnourished children in settings worldwide, it is my assessment that malnutrition of moderate and severely handicapped children is present in the orphanage system. Evidence exists that this has been a systemic, chronic issue. There are a number of contrib-



Fostering good practices in internats begins with training of the nurses.

uting factors to the malnutrition problem in Ukraine internats. At level 4 orphanages it appears common practice for a single staff member to be responsible for the feeding of 12-15 children, several of whom may be handicapped.

Dr. Spector provided the following recommendations to improve the situation of the children:

Since many children with disabilities have unique feeding and swallowing concerns, feeding practices and choice of nutritional products must be tailored to accommodate their special needs. Additional considerations include suboptimal staff-to-child ratios, inappropriately fast feeding times, feeding with inappropriate utensils (i.e. oversized spoon), feeding while children are prone, and poor recognition that food lost out of a child's mouth during feeding must be made up for in quantity in order to ensure adequate caloric intake at each meal. An appropriate solution to this problem will require a multi-disciplinary approach.

The results of the therapeutic feeding with locally available products donated by Nestlé Food Company were striking; severely malnourished children started to show substantial recovery. Subsequently this feeding program has become a so called 'good practice' that later on was successfully implemented in 3 other internats: this turned

out to be very convincing for the policy makers.

DOORS CLOSED TO THE CORRIDORS OF POWER

Until 2006 the internat system was a closed system, based on Soviet practice and laws and regulations. Outsiders had hardly any access to the remotely situated buildings. Even local people in the neighbourhood hardly had an idea about what was the real situation inside. But also the governmental system of Ukraine, in this case the Ministry of Labour and Social Policy was yet reluctant to hear complaints from outside or to consider it prudent or useful to cooperate with civil society organizations. There was no trust between governmental representatives and civil society. When Mrs. Kalandyak started to knock on the doors of the Ministry of Social Policy and Labour in Kiev in 2006 to ask for help and cooperation, these doors turned out to be closed. Even the first internat where the successful feeding program was implemented became closed for 'outsiders'.

BUILDING CIVIL SOCIETY, SOCIAL COHESION AND TRUST

Parallel to the developments in Lviv internats, the International SOFT Federation (ISF) -the network of mainly Eastern European NGO service providers - together with the Path of Life Rehabilitation Centre in Uzhgorod organized in October 2006 a conference titled 'Networks as sources of social capital: Social inclusion of children and young people with disabilities.' The Dutch network of NGO service providers and member of ISF, SOFT Tulip, invited the Dutch SOCIRES foundation to the conference. The SOCIRES foundation had relevant experience in policy influencing in the context of their 'Strengthening Civil Society in Eastern Europe' program. SOCIRES ran a workshop at the conference on lobby and advocacy

for civil society organizations in the field of care.

Parallel to the conference a special working session was organized with Mrs. Kalandyak to work out a specific lobby plan to influence policy makers in Ukraine in order to improve the quality of life of children in the level 3-4 internats. The strategy was to seek for cooperation rather than confrontation. A list of more than 20 'stakeholders' or 'key players' was drawn up, and in the following months each person and organization on the list was visited to inform them about the situation in the internats.

In March 2007, a first round table was organized in Kiev with 18 participants, representing the Ukrainian Parliament, local and regional politicians, several non-governmental organizations (NGOs) including the Ukraine National Assembly of the Disabled and the All-Ukrainian Coalition of People with Intellectual Disabilities, as well as representatives of UNICEF, the Ukrainian Greek Catholic Church, the Embassy of Canada in Ukraine, and international NGOs. It was the first gathering of such a multi-stakeholder platform on the issue of the level 3-4 internats, yet without the participation of the Ministry of Labour and Social Policy. Because of the strength of the gathered group and their commitment to work together this event however reopened the doors for dialogue with that Ministry.

Political support from the Council of Europe was requested in Strasbourg at the Commission on Human Rights by Mrs. Kalandyak and a representative from the European Association of Service providers for the Disabled (EASPD) and the Dutch government showed interest in supporting the process through their MATRA (social transition in the new neighbours of the EU) program.

Clearly, a growing coalition of motivated people and organizations on all levels in Ukrainian society together with international partners was begin-

ning to function. Also in the Ukraine Council of Churches the problems of the level 3-4 internats were discussed.

In December 2007, cooperation with the Ministry of Social Policy and Labour was at last secured. A new round table was organized by the National Assembly of the Disabled of Ukraine. The round table consisted of a network of NGOs active in the field of disabilities, the Ministry of Social Policy and Labour, representatives from Nestlé, the directors of the 23 level 3-4 internats and the head of the Parliamentary Commission on Disability, Mr. Sushkevych. The Ministry was represented, among other officials, by the vice minister Mr. Dyachenko. In this round table the deplorable findings and the results of the examination of the situation in the internats as well as plans for cooperation necessary to improve this situation were openly presented and discussed. Several directors of internats appeared reluctant and even rejected the invitations from the representatives of the civil society to cooperate, whereas several other directors and representatives from the Ministry expressed their interest in cooperation. Member of Parliament Mr. Sushkevych exercised political pressure to stimulate the proposed cooperation.

THE DUTCH MATRA PROJECT HELPS

In 2008, the Dutch government approved the MATRA project for a 3 year period. The main purpose of the project was to create more good practices in the internats, and to cooperate with the government for policy reforms and strengthening of civil society organizations. Already in 2004, SOFT Tulip experts trained specialists from the Dzherelo Rehabilitation Centre in Lviv. Six members of this team formed the basis for a new training program in the MATRA program that started in October 2008. This team was trained by Dutch specialists from SOFT Tulip organizations so that they themselves

could organize the training for the staff in the internats in basic care services, such as feeding, positioning, and play. This so called “train the trainer” program was conducted in three internats and turned out to be very successful. Meanwhile Ukrainian representatives from the Ministry of Social Policy and Labour visited the Netherlands for an intensive program which included a number of visits to various Dutch projects for the disabled and dialogues with Dutch policy makers. In the context of the MATRA project also the Ukrainian National Association of Physical Rehabilitation Specialists was supported through a twinning with the Dutch Royal Association of Physiotherapists and the World Confederation of Physiotherapists. Furthermore, a number of members of the network of Ukrainian Early Intervention Specialists were trained to prevent child institutionalization and to influence governmental policy concerning early intervention.

In September 2009, a new conference was organized in Kiev with more than 130 participants including the vice Minister Mr. Bychkov, MP Mr. Sushkevych, the directors of *all* Ukrainian internats and the directors from the Ministry of Labour and Social Policy of *all* the Oblasts i.e. the administrative districts of the country. This time representatives from the Ministries of Health and Education were also present. The impressive results of the training programs in the level 3-4 internats were presented by three dedicated directors of internats where the pilot interventions were conducted. Also other participants of the MATRA project presented the results of their work. Already during the meeting several directors of the internats expressed their interest to participate in the training and feeding programs. Further cooperation was agreed upon in the evaluation meeting the next day with the representatives of the Ministry of Social

Policy and Labour. This cooperation entailed training in basic care in all internats (level 1–2 and 3–4) and provision of support from Dutch experts to the Ministry in formulating new quality standards for care for people with a handicap in Ukraine. In November that year, SOFT Tulip organized a visit of a delegation from the Ministry and Ukrainian NGOs to the Netherlands to discuss these quality standards with Dutch experts.

In a process parallel to the MATRA project, agreement was achieved with the Minister of Labour and Social Policy and the Minister of Health, after a round table meeting in March 2009, to cooperate in the development and realization of training programs for policy makers. These programs would focus on the issues of malnutrition in Ukraine, with support from the Geneva-based “Sight and Life” charity organization of the Dutch DSM Company (Kalandyak&Bloemkolk, 2009).

A CULMINATION POINT: UKRAINE RATIFIES UN CONVENTION ON THE RIGHTS OF PERSONS WITH A HANDICAP

Yet another conference was organized in October 2008 with the title ‘National Strategy for Implementation of the UN Convention on the Rights of Persons with Disabilities: Policy, Experience and Practice’. This event was arranged on initiative of the National Assembly of the Disabled of Ukraine and in cooperation with the Ministry of Labour and Social Policy and the UN representative in Ukraine, and with support from SOFT Tulip and Socires organizations from the Netherlands. This international conference was again a multi-stakeholder gathering where policymakers such as Mrs. L. Denysova, the Minister of Labour and Social Policy of Ukraine, Mrs. N. Karpachova, Ukrainian Parliament Commissioner for Human Rights, and MP Mr.

Sushkevych shared experiences with international experts like Dr. N. Dobrova-Krol, PhD, who presented the findings of a study (2009) on the detrimental impact of institutional care on the development of children in Ukraine. Also organizations such as UNICEF and WHO, representatives from several embassies and from a broad spectrum of Ukrainian NGOs, including parents’ organizations, participated actively in the event.

This conference was an important step towards the ratification of the UN convention: The Supreme Council of Ukraine ratified the UN Convention on the Rights of Persons with a Handicap and the Optional Protocol to it on December 16, 2009. The convention is brought into action on March 6, 2010.

This UN Convention is a strong policy document for reforming the state dominated care system in Ukraine. It provides policy support for initiatives from civil society and for the reform of the internat system.

LESSONS LEARNED: GOOD PRACTICES, MULTI STAKEHOLDER NETWORKS AND POLICY CHANGES

From 2006 until now, it has been an intensive and complicated process which resulted not only in training and intervention in the internats but also in achieving cooperation between the government and civil society in a mutual effort to find solutions for a societal problem. Four years later in 2010, it can be concluded that the Ukrainian government is more committed than ever to change not only the poor situation in the level 3-4 internats, but to indeed change the whole system of care for the handicapped, and to resolve the problem of malnutrition in Ukrainian institutions. Room will also be given for public – private (non-commercial/non-governmental) cooperation.

The internat system is still there, and laws and regulations are still deeply

rooted in Soviet regulations, but there is now a broad coalition of different actors of the Ukrainian society conscious of the problems and committed to making changes. Cooperation has been initiated with international organisations and experts, and mutual trust has been established, based on good practices, intensive training and long term cooperation.

For a post-Soviet society, the steps taken and the results achieved in the past 4 years are impressive.

To summarize, in the Ukrainian case social cohesion was improved by stimulating the interaction and dialogue within and between civil society organizations and the Parliament, between international NGOs, experts and Ukrainian government and local NGOs, and also between Ukrainian NGOs and UN organizations. Also the combination of expertise (through the ‘train the trainer’ program and involvement of the policy experts from SOFT Tulip organization) and the approach of the SOCIRES foundation to the strengthening of civil society in dialogue and cooperation with government and other policy makers turned out to be very productive.

Crucial success factors during the process described in this article have been the processes of building trust and strengthening social cohesion. Improving the care for the handicapped children was (and still is) a pressing challenge, but to make the necessary policy changes, the relationships between the different actors in society also have to improve. Where initially the state organization saw itself as the only responsible instance for the care of the handicapped, this attitude was successfully challenged thanks to an intensive process by bringing people and organizations together in multi-stakeholder platforms. In these platforms good and bad practices and experiences were shared and presented and mutual cooperation was discussed and agreed upon.

Many personal and informal meetings between governmental representatives, local NGOs, and international experts also facilitated this change, as did a clear strategy of cooperation rather than confrontation.

Policy changes were not considered a *condition* for the cooperation: the dialogue, the building of trust between various actors was the strategy to reach cooperation, which made policy changes possible, durable and practical.

The network of and the built trust between people and organizations involved are still growing and need of course ‘maintenance’. Nevertheless, they form a strong fundament for the crucial future reforms for the benefit of the handicapped children of Ukraine, but also for the social cohesion in the Ukrainian society.

REFERENCES

- Dobrova-Krol, N. (2009). *Vulnerable Children in Ukraine: Impact of Institutional Care and HIV on the Development of Preschoolers*. Doctoral thesis, Leiden University.
- Hanifan, L. J. (1916). *The rural school community center*. *Annals of the American Academy of Political and Social Science* 67, 130–138. Also see Hanifan, L. J. (1920). *The Community Center*. Silver Burdett: Boston.
- Havel, V. (1999). *Speeches*. Retrieved January 25, 2010, from www.hrad.cz/president/Havel/speeches/1999/2604a_uk.html
- Kalandyak, O., & Bloemkolk, E. (2009). Ukraine Government and NGOs committed to fighting malnutrition. *Sight and Life Magazine* 2/2009, 60. Retrieved January 25, 2010, from http://www.sightandlife.org/images/stories/pageimages/content/magazine/02_2009/sight_and_life_0209.pdf
- Ministry of Labour and Social Policy of Ukraine, (2009). *Unpublished internal report*.

Putnam, Robert. (2000). *Bowling Alone: The Collapse and Revival of American Community*. Simon and Schuster: New York.



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