

**Care of the Disabled in Romania**

**Statement of Cristian Ispas  
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**Before the U.S. Commission on Security and Cooperation in Europe**

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**Washington, D.C.**

Good afternoon,

My name is Cristian Ispas and I am the Founder and Director of Motivation Romania Foundation and National Director of Special Olympics Romania. I would like to thank Senator Brownback and the United States Commission on Security and Cooperation in Europe (the Helsinki Commission) and their staff for inviting me to give testimony concerning the status of children and adults with disabilities in Romania.

**Background**

Motivation Romania is a non-governmental organization (NGO) established in 1995. Our primary mission is to create sustainable programs to increase the quality of life of people with disabilities of all ages in Romania. We are governed by a Board of Directors that includes two physicians, one physiotherapist, one person with disabilities and a company manager. We abide by the principle of full transparency and accountability, as documented by our most recent annual report. We employ 74 full-time staff and in keeping with our commitment to empowering people with disabilities, 17 of our staff are wheelchair users.

Initially, Motivation Romania focused on helping young adults with mobility disabilities access quality mobility supports so that they could live independently. Among our accomplishments, we have produced and distributed over 1,700 wheelchairs for children and adults with motor disabilities; provided wheelchair skills and peer group training for at

least 1,000 children, adults and their families; trained a network of wheelchair specialists; and created programs of peer support. Today, our wheelchair production workshop is accredited by the Romanian Health Insurance Agency, which now pays for 20% of the wheelchairs that we donate in Romania.

While support to people with mobility disabilities remains an important part of our mission, over the years, our mission broadened and we began to focus on building sustainable community-based supports for children with disabilities, many of whom had been abandoned in orphanages, often in very dire circumstances.

In the summer of 2001, Motivation Romania Foundation met Mosaic, a faith-based non-profit organization based in Omaha, Nebraska. The Mosaic Foundation has a 93 year history of working with people with disabilities and currently provides services in 15 states and consults with programs in six countries. Mosaic came to Romania to evaluate the needs of children with disabilities who were living in state-operated institutions and to identify a Romanian partner who was capable of creating community-based, family-like residential alternatives. Motivation Romania Foundation was recommended as that partner by the U.S. Agency for International Development (USAID) Mission in Romania. Together, we made our first visit to Placement Center No. 4 Tancabesti. Upon confirming the living conditions of children in that institution, we immediately began formulating a plan to address their dire needs for care, health, education and social integration. In 2002, with approximately \$64,000 in private donations raised by IMPACT, an international alliance founded by Mosaic and NGOS from Great Britain, Norway, Germany and the United States, we began to build housing and develop other services for the children of Tancabesti.

At the time when we started our intervention in Tancabesti, the institution housed 80 children with disabilities in a derelict two-story building serving both as living quarters and special school, and filled with that pervasive smell that no one who has visited such a place

can easily forget. The children that came to greet us during our first visits were wearing ragged clothes and barely any shoes; they had very short haircuts, so it was difficult to tell girls from boys. From the way they were pushing at each other to reach their new visitors, asking to be taken home, one could see that they were craving attention and care.

We were impressed with the lack of any sign that the children had their own toys, pictures or clothes. We were even more stricken by the glass-door toy cabinet, present in only one of the dormitories, having a big lock on the door.

The institution's director guided us on our first tour and explained that the main reason for this situation lay in the insufficient funds available to pay for staff, clothes, medication, and food. She was very open and it was due to her that we were able to transfer the first four children into our temporary transitional center in January, 2003.

We continued to take children out of Tancabesti throughout 2003. Altogether, in 2003, we transferred 14 children, and 22 children followed in 2004-2006. Of the 36 children with disabilities transferred from Tancabesti, 22 now live in Motivation's three group homes, 12 are with foster families, and 2 have been reunited with their natural family. Our largest group home accommodates 8 children while the smallest one accommodates 4 children. We believe this fairly represents a family-like setting bringing with it all of the options of community integration in schools, social interactions such as Special Olympics, and eventually, for many of the children, opportunities for living in more independent settings paired with real vocational options and training. In our model we have no plans to build additional group homes in Ilfov county. We see these settings as opportunities for children to grow and become more independent and as a result move either to foster care settings or be reunited with their natural family. Our track record speaks for itself. Under the USAID grant we committed to supporting 22 children in group homes. As a result of an aggressive effort, we have been able to move 14 children out of the group homes to foster care or family

reunification. This has allowed us to bring an additional 14 children from the institution to the group homes. This movement towards more independent and natural settings has occurred in less than 24 months.

A major reason for our success in creating model community-based programs for these children was Childnet – a partnership between USAID and the Romanian government. Through Childnet, Motivation Romania together with two other Romanian non-profits were awarded consecutive grants totaling 325,000 USD. Building upon our success in developing community-based care for the children of Tancabesti, in 2003. We initiated a Preventative Services Program to support parents caring for children with disabilities in their own homes and communities. We worked in partnership with the Department of Social Assistance and Child Protection of Sector 3, Bucharest, providing occupational therapy, counseling, respite care and in-home support to more than 50 children with disabilities and their families. In addition, we developed a Day Care Center in Cornetu, a village that hosts one of Motivation's group homes. The Center provides education, physical rehabilitation and family support for over 40 children. This Center is special because it serves both children with disabilities and non-disabled children. It is also one of the very few places where Romanian families can come together to participate in programs and receive services focusing on the common needs of their children.

Another important result of our work has been the inclusion of children with disabilities in public schools. Our efforts were successful initially but we encountered resistance from teachers, principals and families of children without disabilities. With help from IMPACT experts, we organized disability awareness trainings and provided support that contributed to increased openness on the part of community groups towards children with disabilities living in our group homes and foster families. Some of the children in our homes also participate in the Special Olympics and have represented Romania at national and

international Special Olympics competitions. Other programs for children with disabilities from institutions include:

- summer camps for children and direct care staff at Motivation's wheelchair accessible camp in Varatec.
- intervention supported by USAID and UNICEF for the children with severe disabilities at the Braila institution featured in the Mental Disability Rights International (MDRI) report including wheelchair provision, physiotherapy and social activities.

In recognition of the quality of our services for children with disabilities from institutions, our staff was invited to train direct care staff from state-run institutions and NGOs from across Romania who work with children with disabilities. Our training team organized events throughout the country from October 2004 to March 2006, training more than 64 direct care staff from institutions, 30 educators from mainstream schools and nonprofit centers, and 36 parents and foster parents of children with disabilities.

An important factor in our ability to create sustainable programs has been our partnership with Mosaic Foundation. Mosaic staff have not only provided invaluable technical expertise but they have, through private donations, provided critical financial support. For example, Mosaic Foundation, working through IMPACT, raised the initial seed money that helped move 36 children out of Tancabesti. Since, then, Mosaic Foundation has helped to raised more than \$500,000 to support our programs and develop new services. With Mosaic's assistance, we also purchased land and build an accessible camp in Varatec, Moldova region. The camp serves children from our group homes, institutions, natural or foster families and their parents.

Mosaic Foundation and IMPACT Alliance not only engage in significant fundraising efforts on our behalf, they provide invaluable, hands-on, staff training and assistance. The

contribution of staff from Mosaic and IMPACT was very important at crucial points during our project, such as at the transfer of the first four children from the institution, or at the time when we started to work with teachers for the school integration of our children. We have benefited greatly from the knowledge, experience and enthusiasm of Mosaic staff from Nebraska, Kansas, Iowa, Connecticut and other parts of the U.S., as well as staff from our German IMPACT partner, all of whom travel to Romania on a regular basis to work with our children and mentor our staff.

### **Opening Doors and Changing Lives**

Motivation Romania is firmly committed to improving the welfare of people with disabilities. Our experience tells us that every human being has the potential to live a full life. Cristina is just one example. Like many children in Romania who have a disability, Cristina was abandoned by her parents and left at Tancabesti, together with her non-disabled brothers Dani and Cristian. When we first met Cristina in 2002, she was 7 years old and weighed 14 kilos. Because she had spent most of her time confined to a crib, she was unable to walk, and she could not eat solid food.

Cristina and her brother Dani were among the first children that we took from Tancabesti. At first, she was very scared and pushed away our staff. However, slowly, she learned to trust and with time she blossomed, in spite of her severe autism. As a first step in helping her regain muscle tone and strength, our staff designed and built her a customized wheel chair. Today, Cristina is able to walk by herself, and she dresses and eats without assistance. Most importantly, she is living in a loving home, with her foster mother, and she sees both of her brothers as often as possible.

## **The Picture Today**

Unfortunately, as “Hidden Suffering,” the recent report by the MDRI makes clear, for every Cristina in Romania, there are still more children living without hope, abandoned in institutions, without adequate support, stimulation or love. Too many of these children live in dire circumstances, confined, neglected and deprived of adequate sustenance and lacking basic medical care. We respect the work of MDRI and other human rights advocates who give voice to the voiceless and provide a powerful impetus for change.

While MDRI has highlighted serious issues and conditions in Romanian institutions, we also believe that progress has been made. For example, the cover of the MDRI report shows a young girl confined to the Braila institution. At the time of the photo, she was 12 years of age. Like many others confined to Braila, she was horribly neglected. I am able to report that Ioana, as well as 36 other children from Braila, are now living in a renovated and well equipped placement center. As the more recent photograph shows, Ioana has gained weight, and her health status and welfare have improved. Our team, Motivation Romania, built an adaptive, customized wheelchair designed for her daily use, improving her ability to eat, to ambulate, and to grow. Her circumstance today demonstrates the potential for children, once neglected in institutions, to thrive.

It was in fact the MDRI report that identified this isolated hospital psychiatric unit housing children like Ioana. The NGO community would not have had access to this information without their investigation. Once made aware of the situation the NGO community in partnership with UNICEF, USAID, and local authorities formed a team to address the deplorable conditions and create an intervention plan to secure the health and safety of these children. However the actual situation, though improved, still does not address the long term needs of these children.

Although mentioned only briefly in the MDRI report, Motivation Romania and other geographically dispersed NGOs are in fact operating centers of excellence throughout the country. Together, we are not only protecting children with disabilities from the abuses and neglect of the past; we are changing Romanian cultural norms and fostering changes in public policy. For example:

- Until very recently, the Romanian government did not have authority to contract with NGOs for services. This law was changed to allow the government to provide base amount subsidies to NGOs for the provision of social services. This represents a major shift in public policy that will stimulate the growth of desperately needed services, if adequate funding is made available.
- Romanian governmental representatives, including Mr. Bogdan Panait, President of the National Authority for Child Protection and Adoptions (ANPDC) recently stated that the government intends to contract to NGOs approximately 40-45% of current services by 2008.<sup>1</sup> A subsequent newspaper article dated August 23, 2006, stated that ANPDC has developed a policy proposal to this end, which is projected to be applied starting next year in five pilot counties.<sup>2</sup>
- The government currently is considering establishing a central payor for contracted services. Under the existing system, there are multiple and confusing funding streams that are difficult to navigate and often have conflicting requirements.
- Some county governments are providing personal assistants and funding for services for children coming out of institutions. For example, the Social Assistance Department in Ilfov county currently pays for 12 foster parents and 3 of our staff who

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<sup>1</sup> Statement in Romanian available from ANPDC Website at: [www.copii.ro/ANPDC\\_comunicat\\_presa\\_ONG\\_1703.doc](http://www.copii.ro/ANPDC_comunicat_presa_ONG_1703.doc). Date consulted: September 7, 2006.

<sup>2</sup> [Serviciile Sociale vor fi Concesionate ONGurilor](http://www.curentul.ro/curentul.php?numar=20060823&cat=7&subcat=100&subart=41838) (Social Services will be Contracted with NGOs). Curentul. Available from: <http://www.curentul.ro/curentul.php?numar=20060823&cat=7&subcat=100&subart=41838>. Date consulted: September 6, 2006.

care for children transferred through our project from the Tancabesti Institution, and we are currently in negotiations with the county to pay for all of the salaries of direct care workers employed at Motivation's group homes. However this is still not enough to cover all costs related to quality residential and educational services that we provide.

## **Challenges**

Motivation's work, as well as the work of other NGOs, stands as proof of the progress that can be made to improve the lives of children and adults with disabilities in Romania. However, more must be done to address unmet needs. Many more children could benefit from services like those that we are providing to Cristina, and that additional preventative services are needed to avoid institutionalization in the first instance. We know, however, that legacies of discrimination cannot be eliminated overnight. It starts with political will, followed by hard work, sustained effort, unflinching commitment and money.

Indeed, an overarching challenge is the need to identify and secure adequate funding to maintain existing services and to create new capacity. Table 1 graphically shows our challenge. When we began in 2002, all of our money was raised from private donor sources. In 2003, we nearly quadrupled our operating budget. However, roughly two-thirds of our funding was attributable to private donations; while the last third came from a USAID grant. For the past several years, private donations and USAID grant funding has been critical to our ability to sustain programming and create new services. However, with the USAID mission leaving Romania, our funding ended in April 2006. Although the Romanian central and local governments' share of funding has increased, it still only represents 20 percent, a small portion of our budget. With accession into the European Union (EU), we anticipate being able to access EU structural funds in 2009. However, given the loss of USAID funding

beginning this year, absent a greater commitment by the Romanian government to fund services for people with disabilities, Motivation Romanian and other similar programs will experience serious budget shortfalls for the next two to four years. Without funding, we will not only have to curtail existing programs, but we will be unable to address the plight of children who remain institutionalized.

Another challenge concerns the need for better coordination between the national and local governments. While public policy has changed at the national level, some local authorities have little or no interest and no incentives to fund or provide services to people with disabilities that meet national minimum, quality standards. The national government, for its part, does not provide sufficient incentives, nor does it enforce its own standards.

The Romanian government has stated in many public forums their desire to build the infrastructure that ensures that people with disabilities in Romania can live full lives in their own communities. Indeed, the presence of President Didilescu here, in these proceedings, indicates that the Romanian government is prepared to make the next step in supporting nongovernmental initiatives.

The Romanian government is aware of the ability of nongovernmental organizations in this country to provide quality services to people with disabilities. In my opinion, it is time to support the replication of these successful models of community-based care for people with disabilities still living in Romanian institutions and those at risk of institutionalization. Through our joint efforts we can extend the opportunities for children like Cristina to other children and adults with disabilities from institutions. What we need is the support of the international community in partnership with the Romanian government to ensure the next steps in our journey to help fulfill our dreams.

Based on our years of experience, we have documented the costs of quality care. To take one child out of an institution such as those identified by MDRI and provide them with

adequate nutrition, clothing, medical care, rehabilitation, recreation, and education costs about \$500 per month or approximately \$6,000 per year.

Let me close by providing you with several recommendations:

1. The Romanian national and local governments must identify and secure funding to sustain existing programs of NGOs and create new capacity to support people with disabilities, particularly people living in institutions. The government should exercise the political will to reinstate this as a major priority.
2. USAID's Childnet program provided a model of cost-sharing between local, national, and international funding sources that assured a high degree of accountability. We would like to see additional US and international support provided to the Romanian government in a way that creates incentives for both the central and local governments to fund existing community-based services and replicate model programs to provide new capacity. This is particularly important in light of the loss of USAID and other international funding and the anticipated gap in funding that we face until the European Union structural funds are operational.
3. The Romanian government must enforce existing laws for children with disabilities to ensure the full implementation at local level of the United Nations Convention on the Rights of the Child (CRC) for individuals with disabilities. It is not sufficient for the national government to say that their only role is to provide guidance and oversight; they must also provide enforcement and accountability.
4. To address the need to identify people with disabilities who have been placed in settings like the one discovered in Braila, the government should conduct a comprehensive assessment of all hospital, psychiatric, rehabilitation units, placement centers, and other institutions to ensure that there is a level of transparency available

to the NGO community and international human rights groups so that the tragedy of Braila is not repeated.

We cannot afford to lose momentum in the establishment of community-based services in Romania. I am confident that with continued international support, the Romanian government working with the NGO community can make continued progress for the benefit of children and adults with disabilities and achieve a quality of life for individuals not previously attainable.

Thank you again for this opportunity. I am happy to answer your questions.