

CARE FOR THE DISABLED IN ROMANIA

HEARING BEFORE THE COMMISSION ON SECURITY AND COOPERATION IN EUROPE ONE HUNDRED NINTH CONGRESS

SECOND SESSION

SEPTEMBER 13, 2006

Printed for the use of the
Commission on Security and Cooperation in Europe

[CSCE 109-2-9]



Available via <http://www.csce.gov>

U.S. GOVERNMENT PRINTING OFFICE

43-969 PDF

WASHINGTON : 2008

For sale by the Superintendent of Documents, U.S. Government Printing Office
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CARE FOR THE DISABLED IN ROMANIA

September 13, 2006

COMMISSION ON SECURITY AND COOPERATION IN EUROPE
WASHINGTON, DC

The hearing was held at 2:06 p.m. in room 226 Dirksen Senate Office Building, Washington, DC, Hon. Christopher H. Smith, Co-Chairman, Commission on Security and Cooperation in Europe, presiding.

Commissioners present: Hon. Sam Brownback, Chairman, Commission on Security and Cooperation in Europe; and Hon. Christopher H. Smith, Co-Chairman, Commission on Security and Cooperation in Europe.

Witnesses present: Adrian Mindroiu, Director of the Directorate for European Integration, Head of PIU, SPO, Romanian National Authority for Persons with Disabilities; Cristian Ispas, Founder and Director, Motivation Romania Foundation, National Director, Special Olympics Romania; and Eric Rosenthal, Executive Director, Mental Disabilities Rights International.

HON. CHRISTOPHER H. SMITH, CO-CHAIRMAN, COMMISSION ON SECURITY AND COOPERATION IN EUROPE

Mr. SMITH. The Commission will come to order. And I want to wish everyone a good afternoon.

I want to thank my friend and colleague, Senator Brownback, who will be joining us shortly, and other members of the Commission.

This is a very, very important hearing. As you know, Romanians have made enormous strides in many, many areas. And as a long-time friend of that country, I certainly welcome these changes.

It has been heartening to see democratic reforms that allow all citizens in Romania greater participation in the political decision-making process and economic reforms, genuinely to improve the quality of life of the people living in Romania.

Ladies and gentlemen, however, "Hidden Suffering," the May 2006 report by Mental Disability Rights International, has shed light on a segment of Romanian society whose lives remain woefully unchanged. For adults and children with disabilities, too many endure an existence shrouded in darkness, shut out of the mainstream of society, and in conditions that are all too reminiscent of the images we saw of orphanages exposed to the public eye in the early 1990s.

I would note parenthetically that having made several trips to Romania, I remember so well when Dorothy Taft and I were there

just a few weeks after the December 1989 revolution. At the time we went to some of the orphanages and were struck by 60 and 70 children lined up, many of whom could not even be turned or handled in a proper way by well meaning, but certainly understaffed orphanages in Bucharest.

And we wondered then, as we now are concerned, about their plight as individuals. They were hurting. Some of them were laying in their own excrement, because, again, there was nobody even there to change them.

As I think many people in this room know, last year this commission held a hearing on Romania's ban on inter-country adoption. The testimony at that hearing was riveting and very moving.

As witness Dr. Dana Johnson from the University of Minnesota testified, and I quote, "contemporary child development research has unequivocally shown that in infancy, hospital or orphanage care for longer than four to six months can cause permanent alterations in cognitive, emotional and behavioral development. A reasonable estimate is that an infant loses about one to two I.Q. points per month and sustains predictable losses in growth, as well as motor and language development between 4 and 24 months of age while living in an institutional care environment."

I would note that the report that we will be spending much of our time discussing today comes to many of those same conclusions. One of those conclusions, and I'll just read it very briefly, was where one of the nurses said—just let me find it—that, how these children were close to death, an MDRI investigator found.

But one of the others said that these kids were actually—let me find it before we move on—that there is deterioration—the bottom line is, to paraphrase it—in the lives of these children when they sit in these places of warehousing.

Of course, it has been proven—here it is. In Timisoara, one of the nurses said, "they become disabled in here." In other words, that's not how they started out. But because of the factors that they face, they become disabled.

Of course, it has been proven, also, that placement in a permanent, nurturing home, by contrast can immeasurably improve their development. We also know that many of the inter-country adoption cases, which were abruptly halted, involved children with critical physical and developmental disabilities.

The children involved have to-date been denied the opportunity for a permanent family, critical medical care and a loving home, in which they have the best chance to develop as they are able.

One of the cases that I worked on personally—and I was joined by some of my colleagues—which thankfully was resolved, at least so far, positively, was in the case of a child with spina bifida who had actually come to the United States, was living with a doctor who specializes in spina bifida.

I chaired the Spina Bifida Caucus in the House, and we worked very hard on those issues and care for spina bifida-afflicted children.

Amazingly, the Government of Romania was in a position where they wanted that child—who was already placed, already here—to go back to Romania, probably to a warehousing situation, to leave

a place where very aggressive care and love was being provided to that child. To me that was absurd.

Sadly, Romania's policies do not take into consideration the best interests of the child. And I say that with respect to my friends in Romania, because I have an enormous respect for the government and for many of the parliamentarians, who I know very well. But it doesn't change the facts on the ground. Facts are stubborn things.

I would also emphasize that is especially true when we talk best interests of the child, a child who has special needs, who could otherwise be a candidate for adoption.

I am particularly troubled by reports that some institutionalized children may lack even basic identity documents, and, therefore, have no chance of being adopted into permanent homes in Romania.

We have received other reports that some children who have no disabilities are nevertheless housed in institutions, because of lack of an adoptive family. Again, the research has shown that institutionalized care can actually cause permanent disability.

Let me just finally say, in reading this report—as I, and I know my colleagues on the Commission have done—this is a serious indictment and cries out, begs remediation, and to do so immediately.

One of the statements made by a nurse in Timisoara—and I quoted it in part, and now I will quote it a little bit more—“we do our best, but it's impossible for us to stop the spread of lice and contagious diseases. I give it an injection, and a baby cries, and I have to keep going. There are too many. They become disabled from being here.”

One of these statements that really grabbed me was when a staff member agreed to unwrap several of the children. One girl, who looked to be about 4 to 5 years old, was actually 17, and weighed no more than 25 pounds. As the staff removed the restraint, her skin came off with the sheet, leaving a raw, open wound beneath it.

Another boy looked to be the size of a baby, and he was 7 years old. He, too, when unwrapped, was wasting away, his legs covered with sores and his fingers chewed and swollen.

So, there's—this is a serious report that needs to be taken very seriously, and aggressively approached with an idea to remediate it and fixing the situation.

I would note parenthetically that no country is beyond reproach when it comes to how they treat their disabled. I remember so well years ago—and it was while I was still in high school—a report that came to light right near my home—it was in Staten Island—when Geraldo Rivera went in with a camera and took pictures of people, many of whom were naked and were being mistreated, as a result of very poor and inadequate—and I would say cruel, in some cases—care.

That was in proximity to my home, in another State, in New York, but right near the State of New Jersey.

That led, and other kinds of exposes, to a very aggressive disability rights movement in this country. It also helped to create ombudsmen and other kinds of permanent oversight bodies—and we have them in New Jersey, we have them in other States—peo-

ple who work on disability issues and do nothing but try to mitigate abuse when they see it.

It also later on had some bearing, the whole disability rights movement, on the enactment of the ADA, the Americans with Disabilities Act, which was landmark, historic, human rights, civil rights legislation for the disabled—which is still in the process of being implemented.

So, again I say to my friends in Romania, all of us have been there, but it's what you do once these kinds of exposes occur. And I would hope that it would be all about reform and making it right for those who have been afflicted with disability, mental or physical.

We are very fortunate today to be joined by Adrian Mindroiu, Director of European Integration in the National Authority for Persons With Disabilities. He has flown in from Bucharest to participate at this hearing. And we are grateful that you were able to come to Washington to share with us your expertise.

I yield the floor to my friend.

ADRIAN MINDROIU, DIRECTOR OF THE DIRECTORATE FOR EUROPEAN INTEGRATION, HEAD OF PIU, SPO, ROMANIAN NATIONAL AUTHORITY FOR THE PERSONS WITH DISABILITIES

Mr. MINDROIU. Honorable Members of the U.S. Congress, distinguished representatives of the NGO community, ladies and gentlemen. I am sincerely honored with the invitation presented by the Helsinki Commission to testify before the U.S. Congress.

I took the decision to respond to this invitation, and have come a long way from Bucharest, sharing the belief this event will be a unique opportunity to inform you first hand on a relevant set of measures that the current Government of Romania, which I proudly represent today, has been undertaking on an issue of unique sensitivity, both to our public responsibility and personal awareness: improving the life of people with disabilities, who are equal in civil rights to us all.

It is also my belief that today's event will be a constructive exchange of perspectives on lessons learned and good practices, to the benefit of our concerned citizens.

I am familiar with the process followed by dedicated defenders of the rights for people with disabilities for over a period of more than 20 years in the United States, which ultimately leads to the Americans with Disabilities Act, a groundbreaking piece of legislation, that admirably transformed the entire American society into a more inclusive and equal opportunity community.

Likewise and parallel progressive development has taken place in the EU countries and, of course, in Romania, too. The very history of the European "acquis communautaire" proves that gradual maturation of the questions in the member states, both in terms of political awareness and Result-oriented policies.

Speaking about political awareness, I feel indebted to refer to the 1990 OSCE Moscow Document in which participating States acknowledge the importance of binding political commitments to ensure the protection of the human rights of persons with disabilities

in the OSCE area, as a consensual political platform to further action and shared accountability on this matter.

My testimony here will be focused on what happened during the last 2 years in Romania. It's the period in which the new government is involved in the reform of the persons with disabilities system.

As a governmental body, we were charged—the National Authority for Persons with Disabilities—to initiate action-oriented policies to elaborate, monitor and control the implementing of the quality standards in the field, to innovate interagency procedures and other chains of cooperation with NGO partners and all the society, in order to effectively and immediately implement policies.

To make a long story short, we had to produce concrete results and unarguable progress, so as to rise up to the standards—world-recognized standards—and compulsory requirements of the EU integration process.

We started from a low level, and we reach today the moment when we have a national strategy—the national strategy was elaborated last year—and the plan of action system, and these two are sustainable by unprecedented financial resources.

For my government, filling the gap of previous years with concern to assistance for persons with disabilities is a key component of developing a comprehensive care system with a long-term vision. The main motivation is to comprehensively integrate the principle of mainstreaming—mainstreaming defined as systemic consideration of the specific needs of disabled people in a broad sense, which have to be respected when designing policies and measures.

Its main objective is to protect, offer equal opportunity and combat discrimination on grounds of disability, against those persons that, due to their social, physical, psychical or economic impediments, cannot provide for their social needs, and develop their own capacities and capabilities to function and participate in society.

I'd like to briefly speak about the quite new legislative framework in Romania, because it is very important what has happened in the last year and a half in the field.

Last year, in 2006, together with our partners, NGOs, the Romanian Government approved the national strategy, which is called the National Strategy on the Protection, Integration and Social Inclusion of Disabled Persons. And the period covered by this national strategy is 2006–2013.

And the name of the strategy is “Equal Opportunity for the Disabled: Towards a Society Without Discrimination.”

Its ultimate goal is to ensure—and the most important goal—is to ensure the right to exercise fundamental civil liberties of persons with disabilities, and ensure a meaningful increase of their life quality.

The core concept of the strategy is the liberty of choice: a person with disabilities has been assured the opportunity to make choices concerning its own life.

Therefore, the National Strategy is the basic platform to ensure a broad and consistent mainstreaming throughout all governmental policies.

Subsequently, in the same year—that means, somewhere in October 2006—the Romanian Government has approved and sub-

mitted to the parliament, a draft law concerning the protection of persons with disabilities. This law was approved by the Romanian Senate at the end of March this year and currently is under debate in the low chamber of the parliament.

We are expecting the law to be approved by the parliament this autumn. So, until December, we have a new and very courageous law concerning the rights of and the protection of the persons with disabilities.

I would like to tell you a little about the national system of social assistance, because the social protection of the persons with disabilities is a part of the national system of social assistance in Romania.

In this respect, in March of this year, the Romanian Parliament approved the Framework Law on the National System of Social Assistance. And this law replaced an outdated legislation of 2001, and all other previous regulations and special provisions concerning the protection of disabled, child protection, elder protection and all other members of the Romanian society who need social protection.

The Framework Law granted the Romanian Ministry of Labor, Social Solidarity and Family the main role in issuing and coordination of social policy at large, and social assistance in particular.

As a result, the Ministry of Labor, Social Solidarity and Family, and the National Authority for Persons with Disabilities, which is an authority under the supervision of the Ministry of Labor, alongside other concerned institutions, participate in policymaking, manage and coordinate the national system for persons with disabilities—national system of care for persons with disabilities—promote their rights and grant methodological and financial support to the social care programs for the disabled person.

An outline on the National System of Protection for Persons with Disabilities follows. The services provided under this system enclose all types of financial aid addressed to disabled persons or their family and their caregivers, as well as social assistance. That means, social services.

And the social services are targeted to maintain, habilitate respective—rehabilitate and develop individual skills, and are provided either at home or in specialized institutions.

The increasing participation of non-governmental organization and other social partners is a specific trait of the care system for persons with disabilities.

If we are talking about the current state of the residential system care for persons with disabilities, I have to inform you that the situation of the disabled persons in the residential system represents the most difficult and sensitive issue we are doing our utmost to cope with on a priority basis.

Statistically speaking, on March 31 this year, in Romania there were registered almost 461,000 persons with disabilities. And this includes 405,000 adults and almost 55,000 children.

Out of this total, almost 18,000 adults and 354 children received specialized care in residential institutions. The rest received care within their family or in a family like environment. At the same date, Romania had 149 residential institutions for disabled adults.

I want to make it—to specify that the National Authority for the persons who are handicapped are dealing with adults with disabilities. That means people over 18.

For the children with disability, their rights are protected, and all the services are provided under the supervision of the National Authority for Child Protection and Adoption, our partners in the Ministry of Labor and Social Solidarity and Family.

The main challenges facing the institutions that provide care for persons with disabilities in Romania are:

First, the majority of our residential institutions are overcrowded, and the living standards in these institutions are very low.

By the way, this summer we had an action, and we evaluated the implementation, the degree of the standards implementation in our system. And the result of this assessment will be published on our Web site by the end of this month. Very, very important for us is how our institutions are implementing the standards that are compulsory.

Second, and the second big problem of the residential institutions is that, in these institutions are a mix of types and degrees of disability. And in each institution we can find people with different types of disability, different degrees of disability. And that makes it impossible to provide tailored-to-fit services for the individual needs identified for each beneficiary.

Other information I want to—that's not presented in my testimony is that I want to inform you that the needs—we create services based on the identified needs for each person. And we have, since 2003, together with some specialists from Holland, we created a scale of support. That means, a scale of assessment to identify the needs of the person.

At the beginning of this year, we realized that this scale does not cover all the needs we need, and the most important one, this scale does not give us information about the needs of persons with mental disabilities and their needs.

That's why we searched, and we updated our scale of supports with a part identified in Wisconsin. The scale of assessment for the persons with disabilities in Wisconsin is very, very close to our needs. And that's because the problems are almost the same as identified there. That means, these big institutions and a mix of types and degrees of disability. So, we started last week to assess again the persons using our new scale.

Third, is the problem—a very, very important problem with—in our staffing of the national institutions for adults with disabilities. The staff employed in these institutions lacks specialized professional training.

And if we are talking about prevention of institutionalization, if we are talking about support to families who have persons with disabilities, a fourth problem is that of day centers, ambulatory centers for rehabilitation of persons—rehabilitation of disabled persons, and all the community services are not enough, are still scarce.

For example, this year we started to create centers for homecare services. But it is the first time. Then we tried to create in five pilot counties this type of services.

What have we done until today?

The National Authority for Persons with Disabilities has closely oriented its actions on identifying solutions for these challenges. Though much remains to be done, I will briefly go through what we have succeeded to achieve so far.

If we are talking about the capacity of national institutions, at the beginning of 2005, each county presented a plan for the restructuring of the old type residential institutions and, of course, those with large sizes and overcrowded.

According to them, these county plans, the number of residents located in these institutions will be reduced, and at the same time, will create alternative community services.

For this, we have now financial support provided by a grant scheme from PHARE 2003. It means around 16 million euros. And national program financed from the national budget of around 3.9 million euros, and a loan granted by the World Bank in May this year of around 18 million euros.

As we speak, this financial assistance is oriented to reorganize and transform almost 48 residential institutions in the very near future.

Why “almost” 45? Because it’s a grant. Everything is on the grant scheme. And based on the project, we can transform 48 or 49 or 47. But the financial means it’s around 48 institutions.

If we are talking about improving the quality of life, in February 2006, the Government of Romania has granted 3.5 million euros to ensure the modernization and indoor remodeling, including the purchase of new furniture and other needs for 45 centers.

Another 14 centers have been benefiting from a financial assistance to ensure the designing for the complete restoration of the buildings. Last month, the government approved the financing of a round 2.9 million euros to complete the repairs for five of the above centers, which already restoration projects have been passed.

And these days, when I left Romania, we have another government decision, which will provide financing for another four centers. This government decision is in the endorsement phase. Probably it will be approved by the government at the beginning of October.

Another problem—a problem very, very important—is the cross handicap problem. And this problem, a sensitive issue, is represented by the people with mental and neuro-psychical disabilities.

Due to the fact that beneficiaries of the assistance and care offered by our Centers for Rehabilitation and Recovery of Neuro-psychical disabled persons, most of them are people with psychical impairments, who mostly require specialized medical care.

And that’s why the Ministry of Health is currently unfolding a comprehensive assessment mission of all residents in the center—not of the residents of the psychiatric hospitals, but for our centers, which I would like to underline again. We provide social services in most of the—in the majority. Of course, are medical care. But most of our services are social type services.

As a member of the Interagency Committee of Mental Health, coordinated by the Ministry of Health, the National Authority for

Persons with Disabilities closely follows the developments on this particular issue.

Moreover, in January of this year, the government has approved a memorandum, jointly initiated by the Ministry of Labor, Social Solidarity and Family and our authority, on the measures meant to solve problems of the institutionalized persons with mental disabilities. Among the most important measures is the approval of building of 10 new residential centers with a capacity up to 50 places each, in which we will want to ensure an adequate assistance for persons who currently reside in overcrowded centers.

Another direction of our reform is to improve the qualifications of specialized personnel. To this end, the national authority has issued nationwide plan to upgrade the professional skills of the personnel enrolled in the care protection system for persons with disabilities.

We are much focused on the program, this year training for trainers.

Mr. BROWNBAC [presiding]. I wonder if we could get this—if you don't mind, if we could get this to a point of closure, and then I'd like to bring up a couple of other witnesses to testify, and invite you to stay at the table.

And I think something that would be most helpful to me, if it would work for you, is to have an interaction then as we question the panelists, and you responding to their questions and assertions, as well.

Does that—would that work for you? Is that acceptable?

Mr. MINDROIU. It's perfect for me.

Mr. BROWNBAC. OK. So, if you wouldn't mind wrapping your testimony up, and then I'll bring these other two witnesses forward.

Mr. MINDROIU. Thank you very much.

**HON. SAM BROWNBAC, CHAIRMAN, COMMISSION ON
SECURITY AND COOPERATION IN EUROPE**

Mr. BROWNBAC. Thank you for that, and thank you for your testimony. I apologize for being late. We had a vote on the floor. I do have an opening statement that I'll submit for the record.

You're welcome to stay there, if you would like, Mr. Mindroi. I'm sorry. My enunciation was not good.

We'll call up the other two witnesses at this time to make a presentation.

It's Cristian Ispas. He's Executive Director of Motivation Romania. Mr. Ispas has worked for 13 years in the Romanian non-governmental sector, founding and building sustainability and capacity in the Motivation Romania Foundation. That's a non-governmental organization providing programs and support to wheelchair users. I'm delighted to have him present.

And then also, we'll have Eric Rosenthal, Executive Director of Mental Disability Rights International, an advocacy group dedicated to international recognition and enforcement of the rights of people with mental disabilities.

He's quoted, as well, in the "New York Times" article May 10, regarding a report done, I believe, by your organization on the situation in Romania.

I want to invite both of you to put testimony forward. We have your written testimony. The most appreciated thing is if you would summarize your statements. And then I personally, and I think Congressman Smith, as well, would like to ask questions that several of you would respond to, and we can get more of a dialogue going at that point.

Mr. Ispas, if you would. Your testimony will be placed in the record as if presented, and if you would like to summarize that, that would be most helpful.

**CRISTIAN ISPAS, FOUNDER AND DIRECTOR, MOTIVATION
ROMANIA FOUNDATION, NATIONAL DIRECTOR, SPECIAL
OLYMPICS ROMANIA**

Mr. ISPAS. Senator Brownback, Congressman Smith, I would like to thank you very much for inviting me to testify here in front of the Commission and share with you my opinion as representative of the NGO community in Romania regarding the situation of people with disabilities.

We are, at Motivation, we are an organization that was created in 1995, to serve people with motor disabilities. We started with production of adapted wheelchairs and with programs aimed at training wheelchair users in independent living skills.

In 2001, we met with a group from the United States called Mosaic, who came to Romania aiming at starting a program to support children with severe disabilities from institutions.

We partnered with Mosaic and with some seed money from them that they raised from American individuals. And then with support from the USAID mission in Romania, we were able to create three group homes, to refurbish a building and transform it into an educational and rehabilitation center.

We built the first wheelchair accessible camp in Romania. We created different type alternative services for children from one institution north of Bucharest in a small community called Tancabesti.

The photo that you received, that you have, show—the first two photos show the situation of the children as we found them in Tancabesti in the summer of 2002. You can see then two photos with our children, who live in the group homes. We have two group homes, one with eight children and another with six children.

You can see the changes in their life as soon as they got the appropriate care.

The initial objective was to transfer 22 children. The fact that we managed to put in place foster care placements and even reunification with natural families, allowed us to transfer 40 more children out of the institution in Tancabesti.

Probably one of the best examples of our work, the best outcome of our work, is Cristina's story—the little girl you will find in the fifth photo, together with our production manager from the workshop. When we went to Tancabesti, she was laying in bed at the age of eight, diagnosed with cerebral palsy, considered being unable to do anything.

At the beginning we provided her with a specialized, adapted wheelchair. And you can see the girl, how she starts to develop. Then we transferred her to our transition center, and in the next

photo you could see her after only 2 months of work with our physical therapy.

Next photo shows Cristina on the day of her baptism. We did that with our children. Most of our staff who are in wheelchairs kind of adopted these children.

Cristina lives now with her foster mom. And you can see the difference between July 2002 and August 2006.

We provided these children not only with residential and educational services. Our children benefit from the Special Olympics program that we have in Romania.

They are now part of the huge family, global family of Special Olympics. And they are recognized and congratulated by the community as real winners in the competitions that we have in Romania—regular competitions in different sports according to their abilities.

Programs like ours, like Special Olympics, like other NGOs offer in Romania, not only identify creative alternative solutions for the children from the institutions, but also influence public policy.

This is why we consider that the legal framework in Romania is quite developed at this moment.

However, we still have a lot of work to do with the central and local governments, with the NGO community, in order to close all those institutions shown in MDRI report.

And what we would need to do that? I mean, if you look at the girl on the front page of MDRI report, and then look on the photo which is next one after Cristina, it's the same girl. When we found her—when MDRI researchers found Ioana in the center in Braila, I think she was 12 years old and she weighed about 24 pounds.

After she was transferred from that psychiatric unit to the new center where she lives, and physical therapists worked with her, she improved a lot. And you see on the next page, provided with an appropriate seating system, a wheelchair, she developed a lot.

So, how much will it cost to have a child like Ioana in this status? We, based on our experience, we think it's around \$500 a month or \$6,000 a year. In the American standards, I don't think that's a lot. For Romania, it is a lot.

The biggest challenges that we think we have in Romania, and how to solve these problems, are the weak cooperation between central and local governments, especially in enforcing the existing laws, and, of course, the financial sustainability.

As you could see from the graph on the left page of this package, we started this program with the seed money from Mosaic and USAID, \$64,000. And then the total amount of money that we received from USAID was \$325,000.

Our partners from Mosaic raised from American individuals. We raised from European donors another \$700,000 to put in place all these programs and to run them up to the end of 2006.

The problem now is that—which shouldn't be a problem—Romania will access European Union, hopefully January 1. But until we will be able to access the structural funds that will come from the European Union, we think that will take time until the government will put in place all the procedures.

So, we think, we estimate that in 2009—and the figures that you see there are 2007, 2008, and 2009—are estimates. So there is a

gap between this moment of 2006 and 2009. Our problem is how to bridge this gap.

So, for us it is essential to find for 2007, for us as an organization. But, of course, for other organizations. But for us, \$200,000 for 2007 to support—to sustain this program. We would like also to replicate it, to see it in other communities implemented by local government and also by other NGOs.

Please let me finish this by making a few recommendations. First of all, we think that the Government of Romania should perform a comprehensive assessment of all institutions and situations of people from institutions. So we don't need an international organization to come and show us what are the problems there.

To make this information transparent for the local community, local and international NGOs, so we can come with plans to solve these problems.

We would like the central government to enforce the existing laws at local level, to convince local governments to allocate budgets to solve these problems.

We would like, as well, the central and local governments to identify funding to sustain the existing programs of NGOs, and also to replicate the model of good practices at the country level.

And finally, we would like to see a program, a model program like the USAID program in Romania, ChildNet, a program of cost-sharing between local and international sources of funding to be replicated, to be copied, to be continued in Romania for the benefit of our children.

And in the end, I would like to read something which I think it's important for this testimony.

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.

Thank you very much.

Mr. BROWNBACK. Thank you, and God bless you for your work.

I had a chance to meet yesterday with Mr. Ispas and to see some of the work and the smiling faces of some of the kids that you're working with. And it's a delight to see that and see the progress being made.

Mr. Rosenthal, thank you very much for joining us, and I look forward to your presentation regarding your report on what's taking place in Romania.

**ERIC ROSENTHAL, EXECUTIVE DIRECTOR, MENTAL
DISABILITIES RIGHTS INTERNATIONAL**

Mr. ROSENTHAL. Thank you very much, Senator Brownback and Congressman Smith, for convening this important hearing.

The human rights of people with disabilities around the world is a subject that has received too little attention. They are among the most vulnerable people in any country. And your willingness to bring the attention of the Commission and the U.S. Congress to this issue is extremely valuable and extremely important.

Before I plunge into our findings on Romania and respond to the important statements of the other speakers today, my organization,

Mental Disability Rights International, has investigated human rights abuses in 23 different countries.

We have published reports on the situation in Turkey, Russia, Mexico, Uruguay, Hungary. It's important to recognize that we are applying the same human rights standards to Romania that we have applied to every other country of the world.

Many of the people who are on our board have dedicated their lives to doing similar work in the United States. And as Congressman Smith properly pointed out, the disability rights movement is a direct outgrowth of finding similar civil rights problems in the United States in our own institutions.

And because we found those terrible problems in our own institutions, we created civil rights laws and oversight mechanisms that require conditions in institutions to be monitored, that require institutions to be closed down, particularly if that allows children to grow up with a family and not in an institution, and to have some form of oversight to make sure. Even a good foster care program needs oversight in the community.

What we have found in Romania, I'm sorry to say, in the 13 years that I have done this, are some of the most serious human rights abuses we have observed anywhere on a grand scale.

We started out investigating conditions in adult psychiatric facilities. And while our report is focused on children—because they're the most vulnerable, and the most immediate action can be taken to save their lives—it is but the tip of an iceberg of a vast, vast problem facing thousands of people whose lives have essentially been thrown away.

There are at least 30,000 children in institutions and well more than that in terms of the adult facilities.

The conditions that we have seen are life-threatening abuses, with inhuman and degrading treatment, and segregation from society. These are basic, fundamental violations of international human rights law. They should not be tolerated in Romania, and they should not be tolerated in any country.

In putting this in a human rights framework, we do it for a very specific reason—not just to generate outrage and public support for reform. But when human rights violations take place, this becomes the currency of international affairs.

It's not just a question of social policy, and who are we as Americans to tell any other country what their social policy should be. But when children are left to die, when people with disabilities are segregated from society for a lifetime, that's where we need to take a strong stand.

It's a critical time, as Romania is being considered for accession into the European Union. And the European Union has identified as one of the ongoing issues that has not yet been resolved the care of people with disabilities in institutions. And we have called on the European Union, certainly, even if it accepts Romania for admission, to continue to monitor these issues, because they have not been resolved, and to ensure that the structural adjustment funding that's used for Romania be used as an incentive and be linked to real reforms.

I have every confidence that reform in Romania is possible. The wonderful work of Motivation demonstrates that children can be integrated into the community.

Mr. Mindroiu himself has a wonderful reputation within Romania for having done some excellent work to provide some models of community care for people with disabilities. Reform can happen in Romania, but there are 300,000 people with intellectual disabilities, and probably close to three million people with disabilities, who are extremely vulnerable.

Our findings in one small institution are representative of a much wider problem. Since the release of our report* in May, our findings have been corroborated. ABC News went in, and a week before the release of our report, just after a couple of days spending some time in Romania, they found abuses every bit as serious as what we found in the Braila psychiatric hospital.

The Romanian newspaper, "Jurnalul National," conducted a series of investigations. And in many different institutions, they found horrendous abuses going on. They called the conditions in the institutions "a refined Auschwitz." That was their term, not ours.

Just last week, ITV News, independent news in Britain, aired findings in institutions. These are institutions where children are kept, and the facilities are so horrendous, the staffing is so low, they generate disability. They are life-threatening. They should not be tolerated in Romania.

We strongly encourage the United States in its foreign assistance, in its political relations and its economic relations to raise this issue at every point. We believe that if we create the incentives for reform, reform can take place.

The Government of Romania cannot solve these problems until they recognize that they exist.

I have to say, the response of the Romanian Government has been shameful up to now. They have denied the allegations of our report. They have said they're outdated. They've said that the problems have been solved, when our findings are both recent and they have been widely corroborated.

Until they recognize that there are life-threatening abuses, how can they possibly solve them?

We in the United States have an oversight mechanism for our institutions and our community services. There is no equivalent oversight mechanism. There is no transparency. There is no accountability.

The Center for Legal Resources found that 100 adults in the Poiana Mare psychiatric facility froze to death. And the response by the government was that it was an administrative problem, by not having enough food and not enough heating.

There needs to be——

Mr. BROWNBACK. When did this happen?

Mr. ROSENTHAL. It's cited in our report. Two years ago, in 2004, the Center for Legal Resources and Amnesty International published reports of 100 people in the Poiana Mare psychiatric facility freezing to death.

* [http://www.mdri.org/projects/romania/romania-May%209%20final__with%20photos.pdf]

And despite international pressure, no individual has been held accountable for that.

Mr. BROWNBACk. Thank you.

Mr. ROSENTHAL. The Government of Romania must recognize the problems in order to reform them.

In addition to creating oversight and rights protection, we are concerned about the direction of reform. While many positive changes have taken place, and some children and adults have been integrated into the community, in the reform process the government continues to build new institutions.

In the testimony of the government today, we learned that in the mental health system the reform process includes building 10 new psychiatric facilities. Their stated goal of the policy reform is community integration. Why are they building 10 new psychiatric facilities?

I confess. In the United States, after abuses were identified, we made many of the same mistakes. We thought, close down the big, horrendous facilities and in the interim, let's create smaller, cleaner, nicer institutions.

Ten years later, we found out that those smaller, cleaner, nicer institutions were just as dirty, were just as abusive, and kept people segregated from society. That is not the direction of reform.

We are watching Romania in slow motion making the same mistakes that were made in many other countries.

They may be intending to do well. They are trying to close down these big facilities. But the direction of big facilities to small facilities is a terrible, terrible mistake.

Congressman Smith, you properly identify when you cited the research literature that shows that every child needs to grow up in a family. It is the loving care of a parent that is necessary for any child to grow up with psychological well-being. Children are permanently damaged by growing up in institutions.

So, according to UNICEF, Romania has built 200 new institutions for children in the last three years alone. They may be moving from big, dirty facilities to small, clean ones, but a new generation of children is being lost.

There needs to be some accountability—not just plans, not just new strategic plans for reform, but accountability for abuses and specific outcomes of seeing children integrated in families.

Thank you very much.

Mr. BROWNBACk. Thank you. That was powerful of a statement.

Let's run the time clock at 10 minutes here, Chris, if you're all right with that.

Do you have—are you being called for a vote or anything? Do you need to—

Mr. SMITH. [Inaudible].

Mr. BROWNBACk. OK. Good, good.

Gentlemen, thank you all for being here and testifying. I've got some questions and some interaction that I'd like to see.

First, Mr. Mindroiu, I want to enter into the record the "New York Times" piece from May 10 of this year, and it's citing MDRI's report. I'm sure you've reviewed this "New York Times" article on the abuses that were found.

Mr. Rosenthal is quoted in this paper as saying, "it was the most horrible thing I've seen in 13 years of doing this work."

How do you respond to that? Do you—is this the situation in Romania?

Mr. MINDROIU. We cannot deny the importance of the work did by Mental Rights Disability International.

And we consider that these problems and these facts MDRI discovered in Romania. It is better to be presented to the authority, to the national authority, the responsible authorities in the time they are identified, and not after a year, or something like that.

Because, for sure, the facts they saw in Romania happened in 2002, 2003, 2004. But, for sure, most and many of these problems were solved by the Romanian authorities.

For example, in Braila, in the hospital they saw and they picture of the girl on the cover of the report, this hospital is closed at the end of last year. There's no hospital there now.

And Mr. Rosenthal told about the ITV News, their broadcast of two weeks ago, and they are talking about one center in Romania. I was the manager of the closing down of the project. I know exactly that this center is closed down since the beginning of this year, and nobody is there now.

This is—I can tell you. Of course, these things were happening in Romania. Probably there are—we can find in one or two places we can find—I don't know what to say. These are mostly things about children, and we are not dealing with children.

But it's not usual to find these things in Romania. And we are working hard not to find these issues, these things now.

Mr. BROWNBACK. If I could comment on our own history in the United States.

You came here and you can go back, and not that far back in the United States history, and find these sorts of problems existing in this country. You could probably find some situations today that you wouldn't be very pleased with, that I wouldn't be very pleased with.

And yet—I mean, I do believe one of the key ways of moving forward is to identify where system problems have occurred. When you're sitting in national government, community government levels, where system problems have occurred, and then try to put in place systems to see that that doesn't occur, or that you just, you break the old models up and try to go at a different model.

But first you have to identify the problem and you have to own it. And we've had plenty of problems here, and there were a number of people, too, for a long period time that advocated that it's too expensive. This is difficult to do, because this takes very individualized care.

My own other experience in this has been that the earlier the problem—particularly a mental health problem—is identified, the more options you have for successfully working with the individual. I mean, it really is key for early treatment and help.

I don't bring you here to beat on you, or to beat on the Romanian Government. I ask you, just in looking at these things—we get these reports and you see these studies, more than anything to identify the problem. And then, what is it that we can assist with?

I have seen your testimony about here's where you're going at this. And if there are specific ways that we or others can help in working with this, we're happy to try to do it.

But it does require—yes, the problem does exist and we're willing to move forward with it.

Mr. MINDROIU. What can I tell you is, after we saw the report, teams from the Ministry of Health, the Ministry and National Authority for Child Protection and from our authority, visited all the locations the report told about and evaluated the real situation. That's why we know what is there now.

And these days, a very large assessment process started and will evaluate all the institutions for children and the persons with disabilities until the end of the year.

And the evaluators are completely independent persons, completely independent, from neither the Romanian Government nor from the local authorities.

It's exactly in the same way you said about—first of all it has to identify what are the problems. And we have to assess again. And we are doing this these days.

Mr. BROWNBACK. Are you—Mr. Ispas suggested a comprehensive review by the Federal Government, by the national government in Romania. Are you—is that what you're saying you're doing, is a comprehensive review by the central government of conditions for mental disabilities?

Mr. MINDROIU. It's our response of Mr. Ispas' testimony. And not testimony, but his ideas. And he is not the only person from civil society who had the same ideas. So, we took—we had the opportunity now to assess everything.

It'll be all the institutions and psychiatric institutions. Everything will be assessed until the end of this year.

Mr. BROWNBACK. And then a report issued by the central government of what you found?

Mr. MINDROIU. Of course. Of course.

And we'll see the needs and the reality.

Mr. BROWNBACK. Mr. Rosenthal, you've heard the testimony about how the problem is being dealt with by the Romanian Government and the view that a number of these institutions have been closed.

Is that—that is a factual statement? It's either—this is verifiable one way or the other.

Mr. ROSENTHAL. What we have seen is a shell game, where people are moved from one institution to another institution. So one institution is closed and they're moved to perhaps a smaller and perhaps a cleaner institution, but to another institution.

In Braila, the psychiatric facility was closed, and they moved them to two smaller institutions. When we visited in December of this year—we first identified the problem in June 2005.

And let me say, the Center for Legal Resources, a Romanian organization, found the problem first in June 2004. They went public. They identified the problem.

We got there a year later and the problem had not been solved after—between 2004 and 2005.

The videotape of that abusive facility, described by Congressman Smith from our report, was taken by me in June of 2005—the most horrendous abuses against these children.

We came back in December, and they had closed down the psychiatric facility, but they moved them to two other facilities. And when we were there we said, well, why haven't you integrated these children in the community? These children need families. Why another institution?

We were told that there were no services available anywhere in the country for children with this kind of disability—no services—and that these children would spend the rest of their lives in institutions.

Before the release of our report, I spoke to one service provider who visited Braila in April of this year, and funding was not available to get those kids out of those institutions into the promised group homes. After the release of the report, the funding miraculously became available.

So, yes, after the spotlight of international attention has been on these particular children in Braila, finally there is some action.

But the children of Braila—those 46 souls whose lives have already been so terribly hurt—what about the thousands and thousands of other children? It has been documented time and time again by other independent investigators that these abuses exist.

To say that the government is now doing an assessment, after all this time—certainly, they need to do an assessment. But there is no independent mechanism to do that assessment. And indeed, the governmental structures are so fragmented, the Ministry of Health doesn't know what's going on in the institutions under the authority of the local governments.

When we asked the Ministry of Health how many people were in institutions, they had no idea. As part of their reform, they're transferring authority over their psychiatric facilities to the local authorities, for which there is no budget.

Their reform plan is simply to take an institution and take it out of Ministry of Health authority and put it into the local government authority, and then they can say there are fewer institutions.

The worst abuses are going on in the mental health system, and no one is taking responsibility for it. The numbers that were given in the official testimony of the number of people with disabilities in institutions here only represent the individuals under his authority at the National Authority for Persons with Handicaps.

There is such a bureaucratic maze of different authorities, there can be no national policy on these matters.

So, there has to be, as Senator Brownback—you identified some recognition of the problem and a way to step back and say, if there is a problem, we have to find some new way of dealing with this that includes the creation of an independent monitoring authority and a mechanism for dealing with this in which a national policy can actually be implemented.

Mr. BROWNBACK. If my colleague would let me just let Mr. Mindroiu respond to this, because I do appreciate your attendance, your being here and your willingness to engage with us on this.

And specifically, do you intend to move people from one institution to another? Or is it—are you moving to an effort to get them from an institution into a family, a group home type situation?

Mr. MINDROIU. This is—there are two different things, for children and for adults. This is for children, the best way is to move it into families. This is for sure.

What we are talking about—

Mr. BROWNBACK. It's your policy that you are doing on a national basis.

Mr. MINDROIU. I distributed a brochure with what has happened, and it's produced by the National Authority for Child Protection.

And these are—in that brochure are a lot of figures, real figures, and what has happened now.

So, for children, the best way to integrate them is from institutions into families—natural families or shelter families, if we cannot find the natural family, or because of traditions and mentality, and so on, they refuse to take a child with disability inside the family.

But when we are talking about adults institutionalized since, I don't know, 1990, with 15 or 20 years of institutionalization, is very, very difficult to take from a residential institution and to sent it to a shelter family, or a natural family.

So, another type of institution like a shelter home is the first step when we are talking about their social integration, because the main idea is, we have persons now in big, overcrowded institutions. They have to—for them we have to do everything, to identify perfectly their needs, and to create the services in the way to include them back into society, even for the employment of them.

And these are making by steps, step-by-step. There are different types of institutions, and each institution has its own mission. So, that's why from a big residential institution it's very difficult to send it back on the first step to the family. And we are talking about an adult over 30 years old, which are staying in an institution since he was 18.

This is what—this is how our policies in this field are going on.

Mr. BROWNBACK. It's been my experience that people that have particularly mental disabilities—certainly physical disabilities, too—really enrich a country. They make us richer, and they make us better.

A lady in my office is blind. And she gives the best Capitol Hill tours of anybody in my office, and I'd put her up against anybody on Capitol Hill.

But she had a very aggressive treatment as a child. And she inspires the rest of my office. Everybody else is just—she actually went skydiving two weeks ago. And so, a lot of other people went out saying, well, if she can do it, I can, too.

And they enrich us.

And I can look back on our history when we didn't really treat people with disabilities as an asset. They were a liability. They were a cost in the system.

And, OK, what are we going to do now?

And we were the poorer for it as a nation. They really do make us better. It's tough. It can be hard and expensive, but they make us better.

My colleague, Congressman Smith?

Mr. SMITH. Thank you very much, Mr. Chairman.

Let me just begin, Mr. Mindroiou. In the MDRI report, a statement is made that the National Authority for Children's Rights told MDRI in 2006 that doctors still encourage parents to give up a child when a baby with a disability is born.

UNICEF concludes from a recent study of recent child abandonment, that the "acceptance and perpetuation of such situations constitutes not only a violation of the law, but also an acute lack of understanding of the child's developmental needs."

My question first is, is that the case?

Mr. MINDROIU. It's very difficult for me to give an answer to this question, because we are not really involved in the child protection system. So, I'm not very sure if—I don't know what to say.

But I do not believe that the doctors recommend to a family to abandon a child with a disability. I cannot believe that.

Mr. SMITH. Is that something that you could get back to us on for the record, so we have, you know—

Mr. MINDROIU. It's easier for me to—

Mr. SMITH. Because it's very important—

Mr. MINDROIU [continuing]. To give you an official—

Mr. SMITH. That's the beginning of—

Mr. MINDROIU [continuing]. An official, right answer from our colleagues from the National Authority for Child Protection, because I do not know exactly what is happening in the system of the child protection.

Mr. SMITH. I would ask that you at least make an inquiry and please get back to us if you get an answer.

I would just note parenthetically that the whole idea of abandonment—you know, neglect and abuse is an extension of a mindset that I believe is employed even before birth, when things or techniques like amniocentesis and other means are used to determine whether or not the child is disabled. And then another abandonment, an abortion occurs.

That mindset then carries forth at time of birth, if these doctors indeed are suggesting an abandonment of such a child.

Mr. MINDROIU. Well, I'm not so sure that the facilities of the hospitals permit to have this information before the child's birth.

Mr. SMITH. OK. Well, let's—

Mr. MINDROIU. There are just a few in this end.

I really do not believe that doctors would do this kind of thing. It's completely against the law.

Mr. SMITH. OK. Mr. Rosenthal?

Mr. ROSENTHAL. Yes, Congressman Smith, if I could add one detail.

In addition to the problem that we identified, of active encouragement of abandonment, there is a problem that the system is entirely overwhelmed. There simply are no community services for newborn children with disabilities. There's no place to go.

The government admits that when a child with a disability is born, there are officially hundreds and probably thousands of children who never leave the maternity ward of the hospital, because there is no support.

A poor mother comes in. She has a child with a disability. She can't get the support she needs.

I have met heartbroken mothers and fathers of children with disabilities who desperately wanted to keep their child with a disability at home. But they lack the support from the government, and felt, well, there are institutions out there where they're assured of getting three meals a day.

And I've spoken to these heartbroken parents who have given up their children to those institutions. It is a very sad thing.

The law of Romania, law 272—the same one that banned the international adoptions—also said that no child under age two may be placed in an institution. So, that's had two perverse results. One, children are placed outside the official system.

When we were in Timisoara, we asked the child protection authorities, are there any children, infants zero to two, in institutions? They said no.

When we went to the hospital and asked the staff at the maternity ward, they said, well, if you go down this street two blocks to the left, there's this institution that they said was for, you know, recuperation of children who are undernourished.

And in that facility there were 62 infants in beds with three staff. They never got out of their cribs. The staff was extremely well-meaning, trying to keep these children alive and clean. And those children had no life except growing up in a crib. It was a very sad thing.

So, there is simply no mechanism set up to help those children and to help families keep those children. Or, to the extent that there is a system, it's overwhelmed.

Mr. SMITH. Thank you.

Let me just ask Mr. Mindroiu a question. You mentioned visits before. And I'm wondering if those visits are done in an unannounced way, whether or not there are protections for whistleblowers, as Mr. Rosenthal just said.

And I was struck by this when Dorothy Taft and I visited the orphanages, right as Ceausescu left and Iliescu came in. They were well-meaning. They were just absolutely, totally overwhelmed by the number of children per helper, per nurse or whatever.

So my question is, when someone might come forward with that information, to whom does she or he address it? Do they make unannounced visits with some real clout?

Because it seems to me that, just like we found with our own institutions where abuse is rampant, it wasn't until you did those unannounced, coming in the door, documenting what is going on, that you get to the bottom of what abuse may be occurring.

Mr. MINDROIU. The responsibility for these institutions, or for the general direction for social assistance and child protection—that means the level, each county level—or in the hospital, to the manager of the hospital.

Normally is, when you go to see something, to have the approval of the responsible for that. But you do not have to take permission one week before. OK, let's go to see. Nothing is—everything is transparent.

Mr. SMITH. But is that regularized? Does it happen—is there like a strike force mentality?

And I would just say before you answer, you know, we have in this country a very, I think well-developed sense that we trust and we verify. Whether it be VA hospitals—I served as Chairman of the Veterans' Affairs Committee for four years. And very often, it was the eyes and ears of those who went unannounced, whether it be the General Accounting Office or some other, or even the veterans service organizations—we assume the best.

But we're always looking out for the vulnerable. And that means that you have to not worry about whether or not it's an affront if you walk in the door.

So, it's a strike force mentality to find—and if somebody does blow the whistle, a nurse, are there protections for her or him to, you know, against retaliation and dismissal and other kinds of retaliatory—

Mr. MINDROIU. Nobody fires an employee who says everything is—in an institution.

But in Romania, there is a law—

Mr. SMITH. Are there protections in law for that person to assert their—you know, the retaliation in law, and say this is a direct—

Mr. MINDROIU. There is no contract which—a labor contract, every labor contract protects the persons, the employees in this respect.

But there is a committee, an anti-discrimination committee, forcing by the law, by the anti-discrimination law, they can control everything and without any permission.

But I do not think it is normal to go to see an institution, to say, OK, I come here to assess, to make a health assessment, to put the closedown, to picture them and after that to publish the pictures.

It's not a very good way for working.

Mr. SMITH. With all due respect, I would disagree that you help both those who administer, and especially those who are at risk. And again, it's not with the intent to embarrass. It's the intent to ensure that their full rights as individuals, notwithstanding their disability, are fully guaranteed.

An adversarial relationship is benign and good when it is done with that as the intent. And that's what my understanding is, what MDRI has tried to do. And to reject it, it seems to me—I mean, everything in here, shouldn't we say, is that true? What are we doing to make sure that it's rectified, if it is true, and to give a full and thorough explanation if it is not?

And I wonder, Mr. Rosenthal, did you get a point-by-point, rebuttal to this? How did that play out?

Mr. ROSENTHAL. We did not. We got broad denials. We were told that there was a parliamentary inquiry when our report came out. We were told that journalists were brought into the institutions and they were found to be clean.

I mean, of course, it's easy to bring journalists into an institution, and of course they're going to be clean on an official visit of this kind.

And yet, ironically, the very government response is an admission. Why are these children in institutions? Why are they in clean institutions at all? After the release of our report and we identified these abuses, there should be efforts to get them out of institutions and into families.

And so, the very government rebuttal was an admission, in a sense, a part of the problem. And that was pointed out to me by a Romanian journalist who was covering this.

We responded to the Romanian Government by saying, look, if you want to conduct an inquiry—we outlined a program for on-site inspections without notice, in which photo and video documentation would be taken. We got no response to the government.

We've called on Europe to continue monitoring. An independent monitoring mechanism needs to take place, whether by us or by Europe, by the United States, by some independent United Nations authority.

These are fundamental human rights at stake. And there is certainly precedent in international law for on-site inspections where very serious human rights abuses are at stake.

Mr. SMITH. Yes, please, Mr. Mindroiu?

Mr. MINDROIU. For sure, the Romanian Government is not against any monitoring, as long as we do not break the law.

Mr. SMITH. But again, we'd be talking about people with the authority to not just visit, singular, but to do visits, plural—hopefully unannounced and in a way that you would have experts looking and knowing what they're looking for.

And there needs to be a division, you know, a pretty bright line of demarcation, so they're not coming from the same ministry, writing up a report that could be a whitewash.

Mr. MINDROIU. From the beginning of next year in the national Framework Law on the Social Assistance, is creating something that is called the "social observer." And the main duty of this social observer as a kind of independent observer is exactly to monitor and to inspect the human rights and all the social services, and so on.

Because, Mr. Rosenthal is right. Yes, you cannot control yourself. This is completely, completely correct. You cannot control yourself.

That's why, for example, we have an inspector in each town, in each county. And this inspector is under our supervision, is our employee. And our inspector is a monitor, the fulfilment of the standards, of the quality standards in the institutions.

But the institutions are not ours. You understand? It belongs to the county council, the local government.

So, it's a kind of independence. But for sure, in this respect, Mr. Rosenthal is right. You cannot control yourself.

Mr. SMITH. Let me ask with regards to from larger to smaller.

It seems to me that it has a surface appeal ring to it. We tried it here to some extent, and it didn't work. And we have found, again, that the placement, particularly with an adoption setting, with people who are ready to adopt a disabled child, or a group home setting where you've got in many cases the disabled running—we have running the setting themselves.

We had a project called Project Hope—independent living for disabled persons—in my district. It is the model of people who are robust. Many of them are afflicted with Down syndrome and other disabilities.

And yet, they work, they use public transportation to get to work, and they live out very, very productive and very happy lives,

and are really, I think, as Sam Brownback said a moment ago, you know, that we value them.

We learn from the fact they have not only coped, they overcome their disabilities. And those of us are put to shame who don't suffer some disabilities when we complain and we see how they overcome their adversity. But they need to be given the setting and the opportunity to do so.

My concern about going to smaller institutions is that it misses by a mile that the people are not well served. It could lead to more abuse, because of a lack of accountability. And that would be a question I would ask.

Doesn't it make it harder when you have scattered sites, to do the kind of oversight and accountability in these smaller home settings? And frankly, where did that come from?

You know, we had a hearing 1 year ago—almost to the day, one day off, last year—on what we believe to be a very cruel provision in law 272 that deals with ending, essentially, inter-country adoption.

The European Commission talks about how Romania has fulfilled its obligations pursuant to the Convention on the Rights of the Child and the European convention. How about the Hague Convention on Inter-country Adoption, designed exclusively, after 10 years of very rigorous and robust debate among the nations of the world, to develop a protocol so that there is transparency in adoption?

Romania turns around—and frankly, I was appalled at this and said it very clearly on many occasions. The House of Representatives did so by way of a resolution, that the idea of Romania's inter-country adoptions has ended, under largely undue pressure from Lady Nicholson, who was the rapporteur for Romania's EU accession.

We find that appalling. And especially now, not just kids who don't suffer handicaps, but it impacts these handicapped children.

So, where did this transfer from larger to smaller approach really come from? And what about the accountability issue, when you have scattered sites and fewer people? And you might tell us, how many people are actually in the oversight business when it comes to the disabled in Romania?

Mr. MINDROIU. Why smaller institutions? I'll first refer to the adult field, and after that I'll speak just a little about the international adoptions, because it's very difficult for me. I was not involved at all in this issue. So, but I can—I have some information, some ideas I hold, something.

First of all, the institutions, actually, institutions for adults are very, very isolated. The small ones are only created in the community.

And this is the main idea, to take them from isolated institutions, to send them to a community, because the tradition in Romania is to hide the disabled—unfortunately. This is a verity. We cannot fight it.

But we can try—and we are doing this—to modify this behavior of most of the citizens. And first of all it is to take disability inside the community, to be seen—persons with disabilities to be seen. That's why our smaller institutions.

But because the first idea is they are highly isolated, far on the hills. And you saw, Mr. Rosenthal, and you cannot say that it is not the truth here.

We are talking about children's disabilities. There are only 350, something like that, in institutions. And this is a true fact. And until 500 children, they are in different type of hospitals, and so on. Just a few are in institutions.

But the main idea is, disabled people to be inside the society, inside the community. Before—this is before they grow and they can live in the community for themselves.

What about adoptions? I don't know. It's a law. It started in last year. We have to try to fulfil the provisions of the law. We'll see.

It's very difficult for me to speak about adoptions. Please believe me.

Mr. SMITH. Let me just—

Mr. BROWNBAC. Yes, I've just got one question. And then I'd just turn the hearing over to you, if you'd like to, Congressman Smith.

Mr. Ispas, I'd just, if I could, ask you to comment on any of the discussion you've had here. You're a practitioner on the ground with some model facilities.

Do you see the trend moving towards more of your facilities? And what's it going to take in the way of resources to see that happen?

Mr. ISPAS. Senator Brownback, I would say that we all know that there is no white nor black. There is a gray in between.

Through my work, I had the opportunity to visit institutions since 1995, with the distribution of wheelchairs. More recently, since I became the National Director of Special Olympics, I have also visited institutions with our programs of Special Olympics.

I would say that we should take into consideration the actual economic situation of Romania. And the alternative that our organization, and other organizations in Romania, propose—community-based services in family-like settings—is an alternative at this moment for Romania.

I don't speak here about institutions which will accommodate 50 people, children or others. One child with disability, 300, 1,000 children with disabilities or adults with disabilities—we have to take care of them.

We, at Motivation and Special Olympics, have 26 people with disabilities employed among 80 staff. We are blessed to have the ability to take care of these children.

I think—and this is why, what I think the Romanian Government should admit—we should unify our forces, admit the problem, recognize it, and then cooperate with international supporters of our efforts, but only after the problem will be admitted, to sustain the actual programs and to replicate them.

This is the alternative. Again, I want to say it again, that we propose. We verified it, and we think that the group home as a transition towards the natural family or the foster family is the most appropriate solution now.

What we hope will happen by 2009, is that we will receive support from European Union, from the structural funds. Forty percent we hope to get from the total cost of the services.

We hope the Romanian Government will understand that it has to allocate more resources and provide another 40 percent of these costs. And then we, the civil society, we have to make available another 20 percent from the individual donors or companies.

Mr. BROWNBAC. And it sounds like, too, there's also some need to really have the discussion with the public, from what Mr. Mindroiu was saying. It has been an objective in the past to hide those with disabilities, and you need a discussion with the public that this is not a liability, this is an asset.

And this is something that we can really celebrate, like you do with Special Olympics. It's a celebration to me, of sorts, of people really overcoming. And that discussion needs to take place, as well.

Mr. ISPAS. Senator, Romania used, before 1989, to be—I mean, seen from inside—seen as a perfect society without disabled. This is why they were hidden in huge institutions in the forests.

The United States has a history of over 200 years of social services. You mentioned earlier that, not a long time ago, only in the 1970s, as far as I know, problems like this existed in the United States.

Romania is a very young democracy of 16 years. We cannot transform all these or solve all these problems overnight. We know it will take time. But everybody from the Romanian society should contribute to this.

We—again, and Motivation will help with equipment. We've adapted wheelchairs. We help with care and also training for staff from other places.

Both at Special Olympics and Motivation, we bring people with disabilities forward. We organize the wheelchair sports on the streets, just for the community to become used to seeing the abilities of people with disabilities, to see what these people can do and how valuable they could be for our society.

Again, that idea that the disabled are probably the most difficult problem of Romania, that we have to hide them because they are ugly—that's started to change. Otherwise, you won't see all these programs that we have now.

The problem is to convince the whole Romanian community—I mean, the government, the civil society—that we have to really involve in providing alternatives for these people.

Mr. BROWNBAC. I want to turn this back over to Congressman Smith. I'm going to have to leave. But God bless you for your work, and I look forward to working with you, Mr. Mindroiu.

This is a tough issue. It's an expensive transition. My experience has been that, once transitioned, everybody is a lot happier, and the cost structure of it declines substantially, as well. It not only declines, you actually have some income that comes in from people being productive in the society.

But it is a tough transition, and I look forward to working with you and others in the Romanian Government to see this on through.

Mr. Rosenthal, I appreciate you and your group and your work bringing this forward. This can't be pretty things to do, but they're important things to do. And I'm delighted that you've done that.

Congressman?

Mr. SMITH. Thanks very much, Chairman Brownback.

Let me just ask a few follow-up questions.

The issue of the National Strategy—and I wonder if you might all want to comment on it—it contains specific dates, who the responsible, principal responsible party is, deadlines, measures. It seems like a very, very comprehensive effort to transition—to use the words of Chairman Brownback just a moment ago—in assisting the handicapped.

It even has a whole section, 2.2, of assuring family support services, something, Mr. Rosenthal, you've mentioned a number of times as being severely lacking.

And I'm just wondering what your assessment is. This was put out in 2005. It's pretty much a 2006 onward looking document, to 2013.

How well is it coming out of the blocks? Is it moving forward?

Mr. Rosenthal?

Mr. ROSENTHAL. We are very concerned, frankly, about these plans. There is no shortage of plans. There have been national strategies. Year after year after year, the Government of Romania has come up with national strategies.

It has brought in EU experts to develop these strategies. And we've seen deadline after deadline come and go.

To have a new national strategy, 2006 to 2008, the specific timetables that are in there—there are no outcomes that they actually have to produce until after the EU accession process is essentially over.

We have been terribly disappointed by many previous reform strategies that simply have not been implemented.

I sat in, in February of this year, at a meeting of the Inter-Ministerial Committee on Mental Health, where all the different ministries that were supposed to be dealing with the mental disability issues got together.

The sub-secretary in the Ministry of Health was there. And he was asked questions by the very senior level advisor to the prime minister.

And she said—and there was a plan in mental health—she said, where in your plan are costs? Where does it say how much you need to do this? How many—she literally said—how much money do you need for toilet seats, to make sure these institutions have the basic hygiene facilities?

He said, I can't tell you. I can't tell you, because we don't know how many people are in institutions. We don't know what their needs are. We don't know what their disabilities are.

There is such absolute chaos at the policy level, it's a very—you know, it's an inch-and-a-half-thick plan, and yet there is such basic lack of information that they can't cost out any specific change.

There was utter exasperation on the part of the advisor to the prime minister who said, I can't say. I cannot turn to the European Union and say that reform is a national priority, unless you give me specifics about how much it's going to cost, when you're going to produce it and what outcomes we're going to see. So, I am very, very skeptical.

There is one national pilot project at Techirghiol. And I'm sure I'm not pronouncing that correctly.

And what I have been told by advocates in Romania, is that the national pilot project that's supposed to be used to help cost this out, is already under-funded, that the staff—the budget for staff—is only at 50 percent of what was in the pilot project, and that the budget that's down on paper is going to run out after another month or so.

So, the pilot projects that they've already set up are under-funded and can't possibly be used as a model for reform.

So, again, we've called on the European Union, and we certainly call on the U.S. Government, to look for outcomes. What are they producing? Another plan that starts in 2006 and ends in 2013 is not an assurance. We want to see human beings moved out of institutions, not into new facilities.

The viewpoint that the official government presented today, that it's an improvement to move people from big institutions into small institutions in the center of the city, is totally at odds with all thinking in the social science field, with evidence in the psychiatric field, with evidence in the developmental disability field.

A person segregated from society will continue to be segregated from society, will become more disabled. Just because their institution has moved from the countryside into the center of the city does not mean that that segregation is not damaging to that person's mental disabilities.

This testimony on page six says, they are now investing in new psychiatric facilities. That is the opposite direction that they are going.

Romania is not a rich country. This is a one-in-a-lifetime opportunity for the infusion of foreign funds, and they are blowing it. They are blowing it on a major scale, and it is a tragedy—a tragedy—to see them using this one-shot infusion of funding to build new institutions.

Senator Brownback talked about how the process of reform is costly. Rarely does a country have an opportunity for an infusion of foreign money to help them with the transition process.

But instead of using it—the problem is that transition requires, essentially, funding two systems at once. You have to keep the old institutions open until you create the community facilities. And therefore, there is a very brief period of a couple years where you have to fund essentially two systems.

But they're not funding two systems. They're reforming the old system by moving them from one institution to the other. They're blowing their one chance.

The views that are expressed by the government are simply not consistent with basic human rights principles that have been opted by the European Union, by the world community.

Just last month, the United Nations finished work on a new draft convention on the rights of people with disabilities. It's an historic document that will help bring the rights of people with disabilities into the mainstream of the international human rights field—a subject that has been overlooked as a human rights issue.

There is one concept, one idea that pervades that convention, that there was world consensus on. And that is, the right to participation in the community, full participation in society, being part of families, making decisions for themselves.

This policy of building new psychiatric facilities, of moving people into new facilities in the center of town, is contrary to basic human rights principles accepted by the international community.

Mr. Mindroiu?

Mr. MINDROIU. First of all, I'd like to inform you that the National Strategy was elaborated only by Romanians together, the national authority together with the NGOs, and Mr. Ispas was there and participated. And he knows exactly how we created the strategy.

The second part is that Mr. Rosenthal knows exactly, to move a person from a residential center. In the family, you need at least six months to work with that person, just for a movement. It's not an object to be moved.

That's why the strategy, because we are talking about people—we are talking about lives—it is between 2006 and 2013.

Why? Because 2013, because it's about the national development plan, and it's about financing the scale. We are talking about seven years of financing. That's why our strategy runs through 2013. It's exactly like in all the European countries, about the financing.

Mr. Rosenthal told us about his participation to a meeting in the Ministry of Health. Yes, it was. But it was the first. And he is right. At that moment, nobody from the Ministry of Health knew how much costs would be involved. That's why in my testimony I told you the Ministry of Health now assesses every person with disability from the psychiatric hospitals and from our centers.

And we do not want to create 10 psychiatric units. We are talking about persons with mental disabilities, which are now residents of very big, overcrowded institutions since, I don't know, maybe the 1980s.

That's why we want to create something special, or to create special services for them and their special needs. And the special and the services we want to create will be based on the Ministry of Health assessment, which is produced in this period.

I don't know. Maybe we won't create 10 centers. But we have the—we propose to the government the financing, to have the financing. After the assessment we'll see what kind of services they want, and we'll create those services.

But as you say, we need financing for that. And we need to have a budget. And the beginning of this year, with a budget, some money for services dedicated only for persons with mental disabilities.

Because there is a thing nobody would like to speak about: the problem with mental health problems—the persons with mental health problems need the same type of community services like persons with mental disabilities.

That's why there is a misunderstanding, the difference between mental disability and psychiatric illness.

And this is—there are no specialists, there are not so many specialists in the world who can say, you are sick or you are disabled, when we are talking about mental disability. It's very, very difficult, because they need medical care and community care. It's not very easy to assess this kind of need.

Mr. SMITH. Is there a sense, even if it's a general assessment, as to how much it would cost to fully implement the...

Mr. MINDROIU. I can tell you, the institutional reform—that means restructuring or closing down the old type of institutions and creating alternative residential services, including group homes and shelter homes and everything—costs around 150 million euros. This is my project, that’s why I know.

Establishing the home care services means that sustainability costs are around 100 million euros, too.

And after that, we have to speak about the training of the staff, because the main challenge of the system is the staff. The staff provides services, not a building.

So, this is my main concern, the training of the staff. And this is—I’d like angels to help us.

Mr. SMITH. Let me ask Mr. Ispas. Mr. Ispas, you might have an answer to this.

Do you agree that the goal should be to move children out of institutional care into family settings? And what barriers exist to do that?

Obviously, all over the world, including the U.S., because of better health care and better interventions, more and more of our disabled are living longer lives and more productive lives. And many of their families, even if they are still living at home, worry about what happens when they die. And that’s a problem we’re facing here in the United States big time.

But, what is your answer to that question?

And secondly—and perhaps others would want to touch on this—when I got elected 26 years ago, the prevalence of autism was one out of every 10,000 in the United States. That was the generally accepted number.

A few years ago, I became aware of what I thought was a spike in one of my townships, Brick Township. So we brought in some experts and we found that the number was significantly higher. But as the work was being done, the Centers for Disease Control and others, including many of the advocates in the autism area, became aware that we probably have a prevalence much higher.

So I drafted some legislation that created centers of excellence within CDC to look and to being to chronicle and to react, as well—mostly on the NIH side.

We now believe that the prevalence of autism is one out of every 166 children.

Now, unlike a baby born, autism often isn’t detected until several months later into that child’s life. And sometimes it’s after an MMR shot, sometimes it’s through some other trigger, perhaps affecting a two-year-old. And so, we have what we think is an epidemic of autistic children.

And I’m wondering if you might speak to what the experience is in Romania. Is it being captured as to how many kids are suffering from it? What are you doing about it?

Because that presents a whole set of independent issues—you know, those kids are warehoused. If early intervention is not undertaken, the prognosis for their life is greatly diminished. The earlier the intervention, the better. And so, I would ask you that.

And finally, the Chamber of Deputies has a proposed law on the protection and fostering of disabled people’s rights. I’m wondering

what the status is of that law, whether or not the NGOs and interested parties have commented on it.

Is it a good proposal? Does it have deficiencies? And all three of you might want to respond on that draft law.

Mr. ISPAS. Congressman, thanks. Could you please repeat the first question?

Mr. SMITH. The first one had to do with those individuals who are now growing into adulthood, over 18, 19, 20. What are the barriers for them? What is Romania doing?

And I would ask you one other question. You mentioned earlier about USAID. In your testimony you said, USAID's ChildNet program provided a model of cost-sharing between local, national and international funding sources.

Well, USAID, as we all know—you know, their funding spigot is coming to a close in Romania.

What's going to happen? I mean, since it's worked pretty well for you, what would be your recommendations to us to maybe—you know, what's the bridge that's out there to continue that kind of funding?

Mr. ISPAS. OK. If I may answer?

The problem of children arriving at the age of 18, and having to leave the institutions for children, to me, it is, again, one of the biggest challenges in Romania.

If you ask me about the children that live in our group homes, I would say that the day we took them out from the institution, we committed ourselves. Since that moment, we have a moral commitment to those children.

We will either find a community alternative for them, independent or semi-independent living, living with their family, or they will stay with us. Because at this moment, if, let's say, one of them is 18 years old, he will be placed in an institution for adults, which is a place we don't want to visit.

I have been in places like this—it's true, not in the latest years. But again, my goal would be to close these institutions as soon as possible.

So, again, that is a real problem for the children who will be 18 years old, who are in other places than group homes managed by NGOs.

Then the question regarding statistics about autism, we have a few children with autism. And just recently, we had a team from Germany who trained our staff in working with these children.

But at the national level, I believe there is no—but I might be wrong—but I think there are no statistics about how many cases of children with autism we have. But I agree, it is a serious problem and we have to approach that problem.

Talking about USAID leaving Romania at the end of this year, as I pointed out in my testimony, this is one of the financial sustainability challenges. We should identify something to put in place of the funding that the American Government, through USAID, provided and helped Romania.

All what we can hope is that we will identify other sources of income that will contribute and will create the incentives for the Romanian Government to come and match this funding, because it should be a common approach for the problem.

Mr. SMITH. Any comment, putting on the draft legislation?

Mr. ROSENTHAL. With regard to draft legislation, again, we have a lot of problems with a lot of the legislation that's on the books. Again, law 272, which I mentioned, explicitly permits children with disabilities, infants with disabilities, to be institutionalized, though it bans other children.

There have been many times when the Romanian Government has specifically asked for the European Union to give it technical assistance on the drafting of legislation, and in particular, in the area of mental health and psychiatric disabilities.

There was a law adopted about four years ago on the rights of people with mental disabilities. It contained many positive rights that said specifically, every person has a right to individualized treatment, to participation in the community.

What the law says on paper is so far different from what happens on the ground. I mean, we go to institutions where there are 100 people in a common ward and they're spending their day sitting in bed. So, the law does not have an impact on the actual treatment of the individuals.

In terms of basic civil liberties, one of the key points in the mental health law was, how do you guide—when can a person be involuntarily detained?

Many people are locked up in institutions for the rest of their lives. And one of the core provisions of international human rights law is that, before a person is detained, they at least have a right to a hearing before an independent authority.

After four years of failing to create norms—what they call norms, what we would call regulations—to implement the mental health law, the Government of Romania, just before the EU accession process closed in April, adopted these norms. They did not respond to the biggest gap in the law.

This was a gap that was identified by the EU experts, failing to create a right to a hearing before a person is institutionalized. And the norms didn't solve that problem.

So, in the area that I am most an expert of, the rights of people with psychiatric disabilities, there are major gaps where the law is not meeting the basic core minimum requirements of international human rights law.

Mr. SMITH. I'd just ask a question with regards to—from time to time—and you see these reports in America—some doctor or nurse—most recently it was a nurse—takes it upon themselves to euthanize people that they consider to have a life that's not worth living.

It has always been a problem with handicapped individuals or disabled persons, that somebody in their misguided view feels that they are better off dead than alive.

Are there any instances in Romania, reported or suspected, where particularly severely disabled persons have been subjected to euthanasia?

Yes, Mr. Rosenthal?

Mr. ROSENTHAL. This is an extremely hard thing to document in terms of the intent to actually kill a person or let a person die.

Conditions that we have seen in institutions—in Braila, for example, when we saw them—were so bad that the natural implication is that many of these children are going to die.

When Center for Legal Resources identified the problem in 2004, they found 51 children. When we got there, there were 46. What happened to those other five children?

In the conditions that I observed in June 2005, there were emaciated children with their bones sticking out from their skin, wrapped from head to toe. Obviously, since we exposed that, conditions have gotten much better, but they have been documented by other people.

We believe that children with disabilities, and particularly who are outside the child protection system, in the psychiatric system, are in such horrendous conditions, that in many situations they are essentially left to die.

So, there are not—there's not a policy, necessarily, that we could identify, or an individual who is choosing to kill them off. But if you let children grow up in those circumstances, they will die.

And the psychiatric literature also identifies—you know, you don't have to deprive a child of food for that child to have what they call failure to thrive, or to die.

The very fact of leaving a child in a crib—they can have all the food available, but without the loving touch of a caring parent, those children will just stop crying. Then they'll stop eating, and they'll start to waste away.

So, the institutions where we saw, that were clean facilities, where there was food, those children are going to die from failure to thrive. So essentially, the impact is the same.

Mr. SMITH. Mr. Mindroiu?

Mr. MINDROIU. So, all we have to do—and I spoke about this, and it is very important—the training of the staff.

Of course, we cannot say it, in our institutions people are starving. It's unbelievable to say that.

But, if the staff are not very well trained, of course, they cannot do anything for a child with a severe disability to eat on his own.

So, we have to work a lot with the staff. And we have to train them, and you have to employ them on a vocational basis, and so on. This is my opinion, and it's my personal opinion. The biggest challenge we have in our field is not to build houses, but to prepare people to work with and to help the disabled to live independently.

But I have only one—if it is possible—only one question I do not understand. Why are children after 18 years old to go into an institution, if they leave you? Why to go into an institution and not a social house, or something like that, to live independently? This is what I did not understand, Cristian.

You said that one child, one of your children, will go for sure after 18 years in an institution. Why in an institution, and not in a social house?

Mr. ISPAS. I think this is a misunderstanding. I didn't say that one of our children will go to an institution. I said that none of our children will go to an institution.

Mr. MINDROIU. Thank you very much.

Mr. ISPAS. I was talking about the situation of children in other places, for example in institutions for children, at the age of 18 or

maybe later, 21, he will be transferred from there to an institution for adults.

Sorry for the misunderstanding.

Mr. ROSENTHAL. But if I may observe, there is a problem of children aging out of the orphanages, who are so disabled as a result of growing up for 18 years in an orphanage, that they need supportive care. And if there is no supportive care in the community, they will go into adult facilities.

We visited many, many adult facilities where children, without necessarily having been born with a disability, just from the very fact of having grown up in orphanages, had been transferred from the orphanage to the adult facility.

And in our report you'll see, we found many young adults in those long-term facilities. So you saw people who had been there 30, 40, 50 years, sitting around. And then you saw a 19-year-old, a 20-year-old.

I remember seeing a young woman who had been—she had been sexually abused as a child, put into an orphanage, never got counseling or care. The staff, you know—it was just a very sad situation, because this child had really, ever since being placed in the institution to get her out of that abusive family situation, had spent her life in the orphanage, knew nothing else and was transferred, then, from the orphanage to the adult facility.

So, it's a very vulnerable age. And many, many children will grow up to live a lifetime in an institution.

Without supportive services, without care in the community, you can't solve the child problem. You're just going to grow them up and leave them to a lifetime in long-term asylum.

Mr. SMITH. Let me just ask Mr. Mindroiu.

There're two ways of dealing with criticism. We find this in the United States all the time, as it's human nature.

You can either deal with a report or with a group that apparently, or seems to be adversarial with an arms length approach, or you can bring them in and say, show us. You're a mirror. We may not accept everything you say, but we do want to hear what you've got to say.

And again, the fact that you are here, I think is very—we very much appreciate that.

But with MDRI, do you have any kind of working relationship with MDRI or other organizations that routinely are critical, to meet with them on a regular basis and take that as a point of, OK, how are we doing? And then engaging in the disagreement or agreement.

But I find it's totally valuable. I do this—we do this as a Congress all the time with groups that have very strong opinions against what the U.S. is doing.

Amnesty International is as critical of the U.S. as it is of other countries, in many cases. And it does form a good backdrop to say, how are we doing, you know, to take our pulse.

Mr. MINDROIU. With MDRI, we do not have any connection, because we didn't know, met him until today, from National Authority. But we have a close relationship with juridical center. They are partners in Romania. And the other partner they had in Romania for the Timisoara visit, the Pentru Voi, for your foundation.

And we are working very close with, for your foundation. And there is a juridical resource center. We finance them projects.

For example, last year we financed a project for their partner in Romania, Juridical Resource Center. And they produced four movies, let's say four movies, with problems in our institutions.

We financed that project. They told us, OK, we'll be tough. OK. We pay to be tough for that, and you will do what you'll have to do and what you intend to do.

And for Pentru Voi Foundation, for your foundation in Timisoara, all the time they are financed by us, because they know how to write projects.

Mr. SMITH. Let me just respectfully request or suggest, some contacts would be helpful, and the higher and the more frequent, the better, so that some of these issues can be resolved.

Mr. MINDROIU. You know, it's like in a marriage. It's better for a husband to say to his wife, or the wife to the husband, OK, you're not right here. So, it's the same thing.

We need the social society to tell us, you're wrong. You have problems. You have to do something, because, you know, you didn't see that. But you have to do it. And it is my duty to show you what is the problem.

That's why I was a little bit—I was not very happy when they saw that in 2004, 2005, and didn't tell us anything about before 2006.

Mr. ROSENTHAL. If I may respond, I never got to Braila before 2005. It was the Center for Legal Resources, a Romanian organization, that identified the problem in 2004. And they went immediately to the government, and the government did nothing.

So, we got our report out as soon as possible. The material in our report was fresh.

In terms of the idea of constructive dialogue, we are very much in favor of constructive dialogue. We are pleased to offer technical assistance. In many, many countries we have done so.

In Mexico, after we identified horrendous abuses in a Mexican facility, the government immediately hired the main psychiatrist on our team to come down to Mexico. They worked very closely. Within six months they had closed one of the most abusive facilities in Mexico.

Just last year we identified a problem in Turkey where they were using electroconvulsive therapy with no anesthesia. Shortly after the release of our report, they abolished the practice.

Many other countries have responded to our reports, though adversarial, in a constructive manner by responding to them.

In the case of the Romanian Government, we've gotten denial, denial, denial and straight misinformation. You keep repeating the same information, that we didn't come to you. I was never in Braila in 2004.

This material is very much up-to-date. It is a national problem. There are children in life-threatening circumstances now.

And we have quite a bit of expertise in how you provide oversight and protection, and we've never been asked for that expertise, because we have been told time and time again, we've solved this problem. This is an ancient problem. Two or three years ago we had this problem, but the problem no longer exists.

So, there has been no basis for us to help or offer our services, when all we've gotten is denial, denial, denial. And frankly, the European Union has been given tremendous misinformation by the Romanian Government about what's going on here. A lot of what they've been told is essentially misleading.

And if we're going to have a public policy discussion on this, there has to be an acknowledgment of these very serious, life-threatening abuses in institutions. And only by that acknowledgment can a problem, a system be set up to end it.

Mr. SMITH. Let me just—did you want to comment? Please.

Because I would hope that this could be the beginning of a new day of cooperation.

Very often, this kind of connection will lead—as you pointed out, in Mexico and elsewhere to concrete action. We all have to be shown what our problems are.

I mean, in my own state we had a problem, not just with mental facilities and abuse—and that's really nationwide—we had problems with nursing homes. And it wasn't until we established ombudsmen with the ability to go in and check, and working aggressively, where you would think there wouldn't be a problem, with abuse that—the elderly were very fearful to say anything, because of the retaliation when somebody would leave.

It's an ongoing problem, but we're working on it every day. So, we all have problems. And I would hope—not to sound trite, but transparency and working with the groups that are bringing forward these very considerable concerns.

As governments, I think our bottom line is we have a duty to protect, particularly the weakest and the vulnerable. And so, I hope that you would work together. And I would encourage it and plead with you to do so.

Mr. MINDROIU. Probably we will work together.

Mr. SMITH. On that note—and again, I want to thank our distinguished witnesses, all three, for being here and for providing such candid answers. And hopefully, a new chapter will be written as we go forward.

If you have anything further as we conclude?

Mr. ROSENTHAL. We would just like to thank you very much for bringing attention to these issues. We know that the U.S. Government policies towards Romania are ongoing. And we just strongly encourage you to raise these in your future dealings with the Romanian Government. Thank you very much.

Mr. SMITH. Thank you so much.

Mr. MINDROIU. We are very happy that you invite us there, and we have the opportunity to tell you what is our vision about the Romanian system, what are our problems, what we want to do, and what are the difficulties. Thank you very much.

Mr. SMITH. Thank you, sir.

Mr. ISPAS. Thank you for inviting me here, and thank you for considering our recommendations.

Mr. SMITH. Thank you so much.

The hearing is adjourned.

[Whereupon, at 4:12 p.m., the hearing was adjourned.]

APPENDICES

PREPARED STATEMENT OF HON. SAM BROWNBAC, CHAIRMAN, COMMISSION ON SECURITY AND COOPERATION IN EUROPE

We have convened this hearing to examine the state of care for the disabled in Romania. By way of introduction to that subject, I'd like to make a few observations.

First, in 1991, the OSCE participating States specifically committed to protect the human rights of persons with disabilities. At the same time, Congress took steps to ensure that the annual country reports on human rights, prepared by the Department of State, would include information about the treatment of disabled persons. More recently, Congress allocated funds in the 2005 Appropriations Act for programs and activities to address the needs and protect the rights of people with disabilities in developing countries.

In other words, the rights of disabled people are an important part of our human rights and our foreign policy dialogue with other nations. It is a measure of society how we treat the most disadvantaged among us.

Earlier this year, Mental Disability Rights International issued a report that was saddening and, in some ways, shocking, for the image it portrayed of neglect and abuse of the disabled in Romania. Today's hearing will allow us to hear more about that report and the findings of its principal author. We will also hear from Motivation Romania, a non-governmental organization working on-the-ground in Romania providing services to disabled adults and children. A representative of the Romanian Government will also share with us his government's perspectives on the challenges of meeting needs and protecting the rights of its disabled citizens.

PREPARED STATEMENT OF HON. CHRISTOPHER H. SMITH, CO-CHAIRMAN, COMMISSION ON SECURITY AND COOPERATION IN EUROPE

Mr. Chairman, thank you for convening this important hearing.

As you know, Romania has made enormous strides in many, many areas, and as a long-time friend of that country, I welcome these changes. It has been heartening to see democratic reforms allow all citizens in Romania greater participation in the political decision-making processes and economic reforms genuinely improve the quality of life for many people living in Romania.

Ladies and gentlemen, "Hidden Suffering", the May 2006 report by Mental Disabilities Rights International, has shed light on a segment of Romania's society whose lives remain woefully unchanged. For adults and children with disabilities, too many endure an existence shrouded in darkness, shut out of mainstream society, and in conditions that are all too reminiscent of the images we saw of orphanages exposed to the public eye in the early 1990s.

As most in this room know, last year this Commission held a hearing on Romania's ban on inter-country adoption. The testimony was riveting. As witness Dr. Dana Johnson from the University of Minnesota testified: "Contemporary child development research has unequivocally shown that in infancy, hospital or orphanage care for longer than 4-6 months can cause permanent alterations in cognitive, emotional and behavioral development. A reasonable estimate is that an infant loses about 1-2 IQ points/month, and sustains predictable losses in growth as well as motor and language development between 4 and 24 months of age while living in an institutional care environment." Of course, it has been proven also that placement in a permanent, nurturing home in early life can immeasurably improve their development. We also know that many of the inter-country adoption cases which were abruptly halted involved children with critical physical and developmental disabilities. They have, to date, been denied the opportunity for a permanent family, critical medical care, and a loving home in which they have the best chance to develop as they are able.

Sadly, Romania's policies do not take into consideration the best interests of the child, and especially not the best interest of children with special needs who could otherwise be candidates for adoption. I am particularly troubled by reports that some institutionalized children may lack even basic identity documents, and therefore have no chance of being adopted into permanent homes in Romania. We have received other reports that some children who have no disabilities are housed in institutions because of a lack of an adoptive family. Again, the research has shown that institutionalized care can actually cause permanent disability.

I welcome our three witnesses here today, each bringing a different set of insights: Eric Rosenthal, who has written a critical report on the quality of care provided for children with disabilities in Romania; Cristian Ispas, who devotes his life, day-in and day-out, to providing services and programs for people with mobility impairments in Romania; and Adrian Mindroiu, a Romanian Government representative working for the National Authority for Persons with Disabilities and who can provide the most up-to-date information on the Romanian Government's initiatives in this area. Mr. Ispas

and Mr. Mindroiu, I especially want to thank you both for coming across the Atlantic to be with us here today.

**PREPARED STATEMENT OF ADRIAN MINDROIU, DIRECTOR OF
THE DIRECTORATE FOR EUROPEAN INTEGRATION, HEAD OF
PIU, SPO, ROMANIAN NATIONAL AUTHORITY FOR THE PER-
SONS WITH DISABILITIES**

Honourable Members of the US Congress,
Distinguished representatives of the NGO community,
Ladies and gentlemen,

I am sincerely honoured with the invitation presented by the Helsinki Commission to testify before the US Congress. I took the decision to respond to this invitation and come a long way from Bucharest sharing the belief this event will be a unique opportunity to inform you firsthand on a relevant set of measures that current Government of Romania—which I proudly represent today—has been undertaking on an issues of unique sensitivity both to our public responsibility and awareness: improving the life of people with disabilities, who are equal in civil rights to us all.

It is also my belief that today's event will be a constructive exchange of perspectives on lessons learned and good practices, to the benefit of our concerned citizens. I am familiar with the process, resiliently followed by dedicated defenders of the rights for people with disabilities in the United States, for a period of more than 20 years which ultimately lead to the Americans with Disabilities Act, a ground-breaking piece of legislation. It admirably transformed the entire American society into a more inclusive and equal opportunity community. A likewise and parallel progressive development has taken place in the EU countries. The very history of the European aquis communautaire proves the gradual maturation of the question in the Member States, both in terms of political awareness and result-oriented policies. Speaking about political awareness, I feel indebted to refer to the Moscow document of 1990, where Participating States acknowledged the importance of a binding political commitment, to ensure the protection of the human rights of persons with disabilities in the OSCE area, as a consensual political platform to further action and shared accountability on the matter.

My testimony will be focused on what has happened during two last years in my country, period which I have been actively involved in the activity of the National Authority for Persons with Disabilities. As a governmental body we were charged to initiate action oriented policies, to elaborate, monitor and control the implementing of the quality standards in the field, to innovate inter-agency procedures and other chains of cooperation with NGO partners, in order to effectively and immediately implement policies. To make a long story short—we had to produce concrete results and unarguable progresses so as to rise up to the European standards and compulsory requirements of the EU integration process.

We started from a low level of accomplishments; we reached the moment when we have a National Strategy and a Plan of Action, sustainable by perspectives of significant financial resources.

For my Government, filling the gap of previous years with concern to assistance for persons with disabilities is a key component of developing a comprehensive care system with a long term vision. The main motivation of our strive is to comprehensively integrate the principle of mainstreaming, defined as systemic consideration

of the specific needs of disabled people, in a broad sense, which have to be respected when designing policies and measures. Its main objective is to protect, offer equal opportunity, and combat discrimination on grounds of disability against those persons that, due to social, physical, psychical or economic impediments, cannot provide for their social needs, and develop their own capacities and capabilities to function and participate in society.

LEGISLATIVE FRAMEWORK IN ROMANIA

To prove by facts the concept we embrace is implemented in real life, may I briefly point out to the basic tools we rely on—the legal infrastructure.

Under the current government, 17 legislative pieces have been approved or are currently under consideration by the parliamentary commissions, out of a total of 38 relevant regulations on the matter concerned. Among the most important, I will mention only the following:

In 2005, Romanian Government approved the National Strategy on the Protection, Integration and Social Inclusion of Disabled Persons for 2006–2013, entitled “Equal opportunities for the disabled—towards a society without discrimination”. Its ultimate goal is to ensure the right to exercise fundamental civil liberties of persons with disabilities, and ensure a meaningful increase of their life quality. The core concept of the strategy is the liberty of choice: a person with disabilities has been ensured the opportunity to make choices concerning its own life. Therefore, the National Strategy is the basic platform to ensure a broad and consistent mainstreaming throughout all governmental policies.

Subsequently, the same year, the Romanian Government has approved and submitted to the Parliament a draft law concerning the protection of persons with disabilities. It was approved by the Romanian Senate and is currently under debate in the lower chamber of the Parliament.

In March this year, the Parliament approved the Framework Law (known as Law no 47) on the National System of Social Assistance, regulating the organization and functioning of the social assistance system in Romania, including the disabled persons. It replaced on outdated legislation of 2001 and all the other previous regulations and special provisions concerning the protection of the disabled. The Framework Law grants the Romanian Ministry of Labour, Social Solidarity and Family the main role in issuing and coordination of social policy at large, and social assistance in particular. As a result, the Ministry of Labour, Social Solidarity and Family and the National Authority for Persons with Disabilities, alongside other concerned institutions, participate in policy-making, manage and coordinate the national system for persons with disabilities, promote their rights and grant methodological and financial support to the social care programs for the disabled.

AN OUTLINE OF THE NATIONAL SYSTEM OF PROTECTION FOR PERSONS WITH DISABILITIES

The services provided under this system enclose all types of financial aid addressed to disabled persons or their care-givers, as

well as social assistance. Social services are targeted to maintain, rehabilitate and develop individual skills and are provided either at home or in specialized institutions. The increasing participation of non-governmental organizations and other social partners is a specific trait of the care system for persons with disabilities.

THE CURRENT STATE OF THE RESIDENTIAL SYSTEM CARE FOR PERSONS WITH DISABILITIES

The situation of the disabled persons in the residential system represents the most difficult and sensitive issue we are doing our utmost to cope with, on a priority basis. On March 31, 2006, in Romania there were registered 460,698 persons with disabilities, among which 405,107 are adults and 55,591 children. Out of this total, 17,959 adults and 354 children received specialized care in residential institutions. The rest receive care within their families and in a family-like environment. At the same date, Romania had 149 residential institutions for disabled adults. In these institutions, the provided social services do their best to fit the types and degrees of disability of each beneficiary.

The main challenges facing the institutions that provide care for persons with disabilities in Romania are:

1. The majority of residential institutions are over-crowded and the living standards in these institutions need important further improvement;
2. A mix of types and degrees of disability are encountered in the same institution, which limits the possibility to provide tailored-to fit services for the individual needs identified for each beneficiary;
3. The qualified personnel needs a quick increase in number by supporting specialized professional training programs;
4. Day centres, ambulatory centres for the rehabilitation of persons with different degrees and types of disability, as well as community services designed to prevent the institutionalization of the disabled are still scarce.

The National Authority for Persons with Disabilities has closely oriented its actions on identifying solutions for these challenges. Though much remains to be done, I will briefly go through what we have succeeded to achieve so far:

1. *Filled to capacity residential institutions*—at the beginning of the 2005, the County Plans for restructuring residential institutions of large sizes have been approved and endorsed by the National Authority. According to them, the number of residence located in these institutions will be reduced at the same time with the creation of alternative community services. The financial support for this reform is provided through means of Phare grants (16 million euro), national budgetary funding (3,9 million euro) and a loan granted by the World Bank (of 18 million euro). As we speak, this financial assistance is oriented to reorganize and transform almost 48 residential institutions in the very near future.

2. *Improving the quality of life in residential centers*—in February 2006, the Government of Romania has granted 3.4 million euros to ensure the modernization and indoor remodeling, including the purchase of new furniture, for 45 centers. Other 14 centers have been benefiting from a financial assistance to ensure the designing for the complete restoration of the buildings. Just last

month the Government approved the financing of 2,9 million euros to complete repair of 5 centers for which already restoration projects have been passed. These days a new Government decision which will provide financing—in amount of 2.3 million euros—for the complete repairs of another 4 centers is in the endorsement phase.

3. *Cross handicap problem*—a sensitive issue is represented by the people with mental and neuro-psychical disabilities. Due to the fact the beneficiaries of the assistance offered by Centers for Rehabilitation and Recovery of Neuro-psychical disabled persons are people with psychical impairment—who mostly require specialized medical care—Ministry of Health is currently unfolding a comprehensive assessment mission of all residents in the centers. As a member of the Interagency Committee of Mental Health, coordinated by the Ministry of Health, the National Authority for Persons with Disabilities closely follows the developments on this particular issue. Moreover, in January this year, the Government has approved a Memorandum jointly initiated by the Ministry of Labor, Social Solidarity and Family and our Authority on the measures meant to solve problems of the institutionalized persons with mental disabilities. Among the most important measures is the approval for construction of 10 residential centers with a capacity up to 50 places each, to ensure an adequate assistance for persons who currently reside in overcrowded centers.

4. *Improve qualifications of the specialized personnel*—to this end National Authority has issued a nation wide plan to upgrade the professional skills of the personnel enrolled in the care protection system for people with disabilities. First stage of this plan is projected for the 2006–2008. During 2006, we are much focused on the program training the trainers.

5. In 2006, another nation-wide program was created to provide the funds for the establishment of 47 ambulatory centres for the neuro-motor rehabilitation of the disabled, both institutionalized and living at home. These centres complement the community type services which are being created and advance in parallel with the reorganization of large capacity residential institutions.

All these measures are only the beginning of the institutional reform of the system, which target the disappearance of large scale institutions and creating the community type services. Other additional measures, included in the National Strategy for 2006–2013, will come into effect in the following years.

Recognizing the need and critical importance of the partnership with of non-governmental institutions in the field of care for the disabled, The Government of Romania has expanded the practice launched by our predecessors, in 2001, through providing financial aid to NGOs on a yearly basis. In 2006, governmental assistance was granted to projects submitted by 22 NGOs, comprising of 835,000 euros. Moreover all the available financing provided by the Government of Romania in the field of social assistance is open both to private and public social service providers, which means that in Romania there is no discrimination between NGOs and state service providers in the field of social assistance. We deeply acknowledge local and international NGOs contribution, as well as the international donors' support, the US included, for remaining

committed to help the Romanian Government's endeavour to seek improvement for people with disability life and to implement our public policies in the field. To this end, their role was and will be very meaningful for the years to come.

Ladies and gentlemen,

My intervention today could not exhaust neither the inventory of the progresses Romania has made within the last two years with respect to the protection of rights for disabled people, nor the difficulties my Government is working hard to bring to a rapid and irreversible solution. As soon as a full fledged member of the EU, Romania will take much advantage of Europe's experiences and EU legislative and financial tools to foster its social policies in service of all its citizens, including of those with special needs. I am confident that also thanks to the joint efforts with our NGO partners, the realities will steadily continue to be transformed, to ensure a life in dignity for people with disabilities in Romania.

The last, but not the least, may I appreciate the interest for this topic in relation to my country here, in the US, and I am ready to respond to other questions of interest.

**PREPARED STATEMENT OF CRISTIAN ISPAS, FOUNDER AND
DIRECTOR, MOTIVATION ROMANIA FOUNDATION, NATIONAL
DIRECTOR, SPECIAL OLYMPICS ROMANIA**

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 approxi-

mately \$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 2008.¹ 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.²

- 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 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

¹Statement in Romanian available from ANPDC Website at: www.copii.ro/ANPDC_comunicat_presa_ONG_1703.doc. Date consulted: September 7, 2006.

²Serviciile Sociale vor fi Concesionate ONGurilor (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.

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, unfailing 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.

**PREPARED STATEMENT OF ERIC ROSENTHAL, EXECUTIVE
DIRECTOR, MENTAL DISABILITIES RIGHTS INTERNATIONAL**

I would like to thank Senator Brownback and all the members of the Commission on Security and Cooperation in Europe for this opportunity to speak today about the human rights of people with disabilities in Romania. I will describe the findings of Mental Disability Rights International's investigative report, *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities*, published in May 2006. The Romanian government must be held internationally accountable for human rights violations against its citizens with disabilities.

Mental Disability Rights International (MDRI) is a human rights organization dedicated to the recognition and enforcement of the rights of people with disabilities worldwide. The rights of people with disabilities have been long overlooked by the human rights community, and MDRI is dedicated to bringing attention to the concerns of this population that is subject to stigma, economic and social marginalization, legal discrimination, and segregation from society in much of the world. MDRI has documented human rights abuses in 23 countries and we have published reports on human rights abuses against people with disabilities in Turkey, Peru, Kosovo, Mexico, Russia, Hungary, and Uruguay.

In our report, MDRI holds Romania to the same, universal human rights standards that we use to assess every other country. The life-threatening abuses, the extremely inhuman and degrading conditions of detention, and the large scale on which people with disabilities are segregated from Romanian society in stands out as some of the most serious and pervasive human rights violations MDRI has found anywhere. There are at least 30,000 children detained in institutions—and probably many more—who will be developmentally and psychologically scarred for life as a result of their improper and unnecessary placement in Romanian institutions. There are an even larger number of adults whose lives have been thrown away as they languish in almost total inactivity in abusive facilities.

These hearings come at a critical time when Romania's treatment of children and adults with disabilities is under intense international scrutiny. The European Union (EU) is now reviewing Romania's human rights record as it considers admitting Romania as its newest member state. MDRI has called on the EU to require concrete action by the Romanian government to end the abuses we identified and to fully integrate children with disabilities into the community. Similarly, I urge the United States to take a stand on these issues. Foreign assistance, trade, and political cooperation should be linked to ending these human rights abuses in Romania. Romania can end these abuses—if the international community takes a strong stand. The world community would not tolerate such extreme abuses against any other population.

The factual findings of our report are based on MDRI's investigation in Romania from February 2005 through February 2006. Our findings are as follows:

MDRI's investigation found that children are detained in numerous adult facilities. While the rights of all people detained in these institutions are being violated, children are particularly at risk.

I have visited institutions in twenty countries around the world. What I witnessed at the adult psychiatric facility Braila was the most disturbing horror I have ever seen. These children were close to death.

In 2004, the Center for Legal Resources, a Romanian human rights organization, found 51 children living in the Brailia psychiatric institution in atrocious conditions. The Center wrote to the government to demand change. When MDRI visited Braila in June 2005, we found 46 children living in horrendous conditions. I personally observed children tied to cribs, wrapped head to toe in sheets used as full-body restraints, with open wounds and bed sores all over their bodies, malnourished, and near death. We found teenagers so emaciated that they looked like they were 3 or 4 years old. Their spindly arms and legs were twisted into contorted positions from disuse and atrophy. Their eyes had sunken deeply into their skulls, and they stared blankly at the walls. Ribs and other bones stuck out from their skin, which seemed to sag from their bodies without any extra flesh.

Staff agreed to unwrap several of the children. As the staff removed the restraints on one girl, her skin came off with the sheet, leaving a raw open wound beneath it.

I ask members of the Commission to look at the cover of MDRI's report, *Hidden Suffering*, that we have distributed today. The emaciated child in this picture is a teenager who weighed less than 30 pounds.

- At the urging of the EU, Romania has begun reforming its child care system. Yet children with disabilities have often been left behind. Romania adopted much-publicized legislation, Law 272, which bans placement of babies in institutions. But there is a loophole in this law that permits any child with a "severe disability" to be institutionalized. The law is commonly used to institutionalize babies with even the most minor disabilities. MDRI also found babies without any disabilities detained in institutions, a clear violation of this law.

In February 2006, MDRI found 65 infants—with and without disabilities—in an institution for children in the city of Timisoara. One nurse working this facility told us:

I have worked here for twenty years and my heart has turned to stone. I thought it would be better after the revolution, but it is not. We do our best, but it is impossible for us to stop the spread of lice and contagious diseases. . . . I give an injection and a baby cries and I have to keep going. There are too many. They become disabled from being here.

There are so few staff at this facility that the children never leave their cribs. These children are becoming psychologically and developmentally disabled as a result of this lack of attention. Institution staff informed MDRI investigators that some children could easily be adopted, but they are stuck in the facility only because they lack identity papers. It is impossible to say how many more facilities of this kind exist in Romania.

- As part of Romania's reform, many children with disabilities have merely been moved from large to small institutions. While these facilities are newer and cleaner, they are still inappropriate for children and will contribute to increased disability. Extensive

Romanian and international funding has gone into building new institutions, draining scarce resources from the process of creating foster care and other services necessary for the community integration of children with disabilities. According to UNICEF, nearly 200 new “small” institutions have been opened in recent years.

The government of Romania claims that it has reduced the population of its institutions for children from 100,000 to 30,000 in the last few years. Our investigation calls into question those numbers. There is no way to tell how many children are detained in adult facilities and how many children have merely been transferred to smaller institutions now called “family-like” environments. We visited one facility for 25 children in the center for Timisoara, where children had been moved after a notoriously abusive orphanage had been closed. The local child protection authorities referred to this facility as a form of community integration. In fact, these children were entirely segregated from society. We observed children sitting around in rooms doing nothing. Deprived of a family and of loving care, the children who grow up in these facilities will become more and more disabled.

As the psychiatric literature reveals, it is not just physical deprivation that can lead to loss of life. Emotional abandonment—resulting in “failure to thrive”—causes both emotional and physical damage to children at a critical time in their development. Even children who receive adequate food in clean institutions become disabled; some children are so emotionally neglected they will not eat—they may become malnourished and die.

In addition to the 30,000 children acknowledged to live in institutions, at least 9,000 babies are abandoned each year—a rate of abandonment that has not changed over thirty years since the Ceausescu era. Romania has created a “maternal assistance” program to provide foster care for children with disabilities, but it cannot meet the enormous needs of the large number of abandoned babies. The government admits that at least 700 abandoned children languish in maternity wards of hospitals—other sources put the number much higher. There is a particularly large gap in services for children and adults with disabilities. Throughout the country, we found children and adults with disabilities detained in institutions because of the lack of community supports. Most children with disabilities face the prospect of life-time institutionalization unless major changes take place.

While the government of Romania has worked hard to demonstrate to the world that it is reducing the size of its orphanage population, what we have observed could be described as an enormous shell game—where children are being hidden as they are moved from one institution to another.

The Sub-Secretary in charge of Mental Health at the Ministry of Health admitted to MDRI in February 2005 that he has no way to estimate the number of children in adults facilities. According to the Sub-Secretary at the Ministry of Health:

It is not clear how many patients there are with disability in psychiatric hospitals. We do not know why or on which basis people are kept in different institutions. There are people with disabilities and without disabilities in institutions . . . patients’ rights are not

well known, even by the doctors. . . . All institutions are overcrowded.

One of the greatest obstacles to reform—or for the implementation of any effective national policies regarding people with disabilities in Romania—is that responsibility for care of children and adults with disabilities is divided among numerous ministries and authorities at the local and national level. Nor is there any independent mechanism for monitoring human rights conditions in institutions or assuring quality of care. The Sub-Secretary told us:

To date, I have never received any complaint about what is going on in the mental health system. There is no mechanism in place to bring complaints to me.

Behind the closed doors of institutions for children and adults with disabilities, terrible human rights abuses take place. Yet there is no accountability for abuse, even when documented and publicized by human rights organizations in and outside of Romania. For example, the Center for Legal Resources and Amnesty International documented that more than 100 people died of exposure in the Poiane Mare psychiatric facility in 2003, and 17 people died in the facility in February 2004. To date, no one has been held accountable. The Romanian government still insists that people died of natural causes or “deficiencies of an administrative nature.” In papers submitted to the European Committee for the Prevention of Torture, the Romanian government described as “administrative deficiencies” such practices as the “lack of heating in the patients’ rooms, hypo-caloric food, insufficient and unqualified staff for the care of psychiatric patients, lack of good medicines, extremely reduced possibilities of pre-clinical investigation. . . .” etc

The government of Romania cannot remedy human rights violations that it continues to deny. The government has shamefully responded to MDRI’s report by simply denying the facts we have presented and claiming that we have fraudulently used old video. In an echo of communist-era thinking, officials have accused MDRI of being part of a conspiracy for one ulterior motive or another. Since the release of our report, however, our findings have been extensively corroborated by independent journalists from Romania, the United States, and Europe. ABC News broadcast video footage taken in early May 2006 showing institutions for children every bit as abusive as those depicted in MDRI’s report. The respected Romanian newspaper, *Jurnalul National*, conducted a series of powerful independent exposes of institutions for children, labeling them “a refined Auschwitz.” A group of 33 service providers for children in Romania took out a full page advertisement in the *Financial Times* to protest human rights abuses against children in Romania’s child care system. Just last week, ITV news broadcast another two-part documentary on abandoned babies in abusive Romanian institutions. The *Sunday Mail* and the *Times of London* have also run similar stories.

There is a humanitarian crisis facing people with disabilities in Romania. This crisis is taking place on a grand scale. Immediate attention is needed to protect children and adults with disabilities from these life-threatening abuses.

MATERIAL SUBMITTED FOR THE RECORD BY HON. SAM BROWNBACK, CHAIRMAN, COMMISSION ON SECURITY AND COOPERATION IN EUROPE

[The New York Times, Wednesday, May 10, 2006]

ROMANIA'S ORPHANS FACE WIDESPREAD ABUSE, GROUP SAYS

(By Craig S. Smith)

Children tied to cribs and chairs often cold, underfed and smeared with their own feces: Romania has tried over the last decade to erase those images of its orphanages seen around the world.

But thousands of children in government-run institutions are still living in conditions that are little changed from a decade ago, investigators for Mental Disability Rights International found.

Writing in a report to be released today, just days before the European Union issues its final assessment on whether Romania has met human rights and other membership standards, researchers described an eerie silence in a ward where 65 abandoned children were housed, because children who do not receive attention when they cry learn to stop crying.

In an adult psychiatric hospital, investigators found some children wrapped head to toe in sheets used as full-body restraints; When the staff agreed to remove the sheet on a 17 year-old girl, the report states, "her skin came off with the sheet, leaving a raw open wound beneath it."

"It was the most horrible thing I've ever seen in 13 years of doing this work," said Eric Rosenthal, executive director of Mental Disability Rights International, a Washington-based group, and the co-author of the report.

Mr. Rosenthal's group is urging the European Union to insist that Romania take immediate action to end the abuse before next year, when the country hopes to join the union.

The strategy has worked before. In September 2005, as Turkey began formal talks to join the European Union, Mental Disability Rights International released a report on the use of electroshock therapy without anesthesia in Turkish psychiatric hospitals. Turkey has since ended the practice at its main psychiatric hospital in Istanbul and is addressing other problems raised in the report.

Simona Pella, an official at Romania's National Authority for the Protection of Children's Rights, said she had not yet seen the report, but disputed its findings.

"We are talking about a report made by a nongovernmental organization, and it's their opinion," Ms. Pella said by telephone from Bucharest. "They are not talking about facts in all of Romania, just about some cases in two counties.

While the number of children in the country orphanages has dropped to about 30,000 from 170,000 in the early 1990's, many children particularly those with mental or physical disabilities, have simply been moved into less visible, though equally appalling, institutions, including adult psychiatric hospitals, Mental Disability Rights International found.

"Romania was rushing to show that it had decreased its orphanage population, but it left children with disabilities behind," Mr.

Rosenthal said in New York on Monday. He said there was no way to estimate how many children were living in the conditions described in the report.

Romania's orphanages are a legacy of Nicolae Ceausescu's rule. He banned birth control and left under-financed state institutions to care for the wave of abandoned children that followed. After he was assassinated in 1989, as Communist rule ended the horrors of the system were exposed to the world.

Much has improved since then. Foreign aid organizations rushed in, and European and American advisers worked with Romania's new government to help put abandoned children up for adoption or place them in foster homes. In January 2005, intending to bring the country in line with European Union practices, Romania passed a law that prohibited placing children under 3 in institutions unless they were "severely disabled." The law also blocked foreign adoptions in the hope of cutting down on child trafficking.

But, according to the report, about 9,000 babies are deserted in Romania every year, one of the highest rates in Europe. The country's foster care and adoption programs strain to keep up with the number of children who need their help.

As a result, abandoned children with even mild disabilities and some with none at all are being kept in maternity wards or other hospital-associated institutions until they are old enough to be moved to an orphanage or other institution. In February, investigators for the group found 65 infants, some without any disability, being cared for by three people at a "nutritional recuperation center" in the western city of Timisoara.

The children were confined to their cribs most of the time, the report states. Some of the older ones rocked back and forth, banging their heads or "making the rhythmic sounds from dislocated jaws common in children left lying down for extended periods," the report said.

Karen Green McGowan, a registered nurse who assessed many of the children cited in the report, said the early neglect led to disabilities later on, making it likely that many otherwise normal children would end up institutionalized for life.

"What they're doing there, in my opinion, is manufacturing disability," Ms. Green McGowan said. "By the time they're in their teens, these kids are being moved into institutions."

Ms. Pella, the government official said that her figures showed that 5,000 children are abandoned each year but that half are eventually reunited with their families. Foster care and adoption programs handle the rest, she said. Only those who require medical care stay in the hospital or are institutionalized, she said.

But the report documents several cases of older children, some kept in permanent restraints, in adult facilities, including the St. Pantelimon adult psychiatric hospital in the eastern city of Braila.

"We found 46 children in Braila one near death, that looked like they were from Auschwitz, just skin and bones," Mr. Rosenthal said.

"They found bed ridden teenagers so emaciated that they looked like they were 3 or 4 years old," their limbs atrophied and contorted from disuse.

Instead of giving the children attention, the report states, the hospital staff tied them down.

After Mental Disability Rights International and a Romanian organization notified the government of the situation, the children were moved to two smaller institutions for children, the report stated. But the more disabled of them remained isolated, without even a bathroom for toilet training. All of them, up to the age of 17, use diapers.



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