
Decentralization of Services for People with Disabilities in Central Europe:

An Account of the Technical Assistance
Offered to Five Countries

September, 1995



Human
Services
Research
Institute

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Prepared by:

John Agosta, Ph.D. and Bruce Blaney, M.S.

Human Services Research Institute
525 Glen Creek Road NW (Suite #230)
Salem OR 97304
503-362-5682
503-362-7729 (fax)

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge MA 02140
617-876-0426
617-492-7401 (fax)

Prepared for:

The American Jewish Joint Distribution Committee
International Development Program
711 Third Avenue, NY 10017-4014
212-687-6200

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Acknowledgments

Coordinating work across multiple time zones, languages and cultures is hard work. We learned that it takes patience, attention to detail and a commitment to planning ahead. Like others, I suppose, our team was strong in its resolve, showed patience and tried to attend to the small things. But we could never seem to plan far enough ahead. Busy schedules, time differences, uncooperative fax machines, government bureaucracy, and other factors all worked to unravel our plans.

Yet we succeeded at accommodating many of the requests made of us and to visit Bulgaria, the Czech Republic, Hungary, Poland and Slovakia. In each country we participated in discussions that we hope will inform each nation's plans to decentralize government, and to initiate social policy that promotes social integration for people with disabilities.

We could not succeed, however, without the committed help of so many individuals from several countries. This was a multi-national effort. We are most grateful to Helena Jungova of the Czech Republic for serving as our project coordinator. Helena worked hard to assure that the logistics for our visit came together, even while fax machines failed to respond or phones went unanswered. Without her efforts, the technical assistance visits would not have been completed.

In several of the participating countries, individuals stood up and lent us a hand. Lajos Kullmann, for instance, saw to it that we had an itinerary for Hungary and distributed the information we provided to others in his country. Diana Mitsova did likewise in Bulgaria, and also tirelessly translated for us for an entire week. In Poland, Wojtek Otrebski and Andrzej Juros patiently worked with us to establish a workable schedule and to assure that our visit was useful. In Slovakia, Viera Tomanova rescued our plans when we wondered if the faxes and phones would ever work.

We must also extend thanks to staff at the American Jewish Joint Distribution Committee. Henryka Manés offered support whenever she could and assured the availability of funds for our technical assistance visits. Pesach Gitelman (no longer staff at the JDC) offered his consistent support and guidance whenever we asked, and his good humor was always welcome. But we must extend a most hearty thanks to Marcia Presky whose persistent interest in this effort added greatly to its success. More than anyone, Marcia offered us the guidance and gentle push that was occasionally needed to make certain that the technical assistance visits went well. You see, she was quite cognizant of the need to plan ahead... way ahead.

Finally, we give thanks to the great many people who took time from their days to contribute to the project or participate directly in it. From the United States several people took time to talk with us and to donate materials that we could distribute. And in Central Europe, government staff, professionals, people with disabilities and family members all took time to come and speak to us -- often through a translator. Thank you all, and we hope the modest assistance we offered will contribute to your efforts.

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- B: Memorandum Summarizing Impressions while in Bulgaria
- C: Prototype Letter to Request Surplus Equipment for Bulgaria
- D: Full Text of the *Pushing Toward Community...* Prepared for the Czech Republic

1. Background to the Technical Assistance Visits

On April 6-7, 1995, AJJDC collaborated with the Human Services Research Institute and the Czech government to convene a symposium on decentralization of social services. The meeting was held in Prague of the Czech Republic and was attended by individuals composing country teams from five central and east European countries, including Bulgaria, the Czech Republic, Hungary, Poland and Slovakia. Facilitating discussion were others from the United States, Israel, Norway and Denmark.

As a condition of their participation, each country team was asked to articulate a particular problem concerning social services and decentralization that they wanted to address, and to make a related request for technical assistance. Subsequently AJJDC and HSRI staff reviewed the requests and set plans for delivering some amount of targeted technical assistance to each of the five counties. While relevant printed materials were compiled and sent representatives of each country team in August 1995, all actual visits to provide assistance were completed from September 13-28, 1995. Two HSRI staff conducted these visits, with John Agosta visiting Bulgaria, the Czech Republic and Hungary, and Bruce Blaney visiting Poland and Slovakia. In addition, David Janner-Klausner of AJJDC in Jerusalem also took part in the visit to Bulgaria. What follows is a review by country of the technical assistance requests made, including HSRI's intentions for providing technical assistance, and an overview of the resulting technical assistance visits.

2. Technical Assistance Visit to Bulgaria

Initial Requests for Assistance and Our Intentions

During the April symposium on decentralization in Prague, the Bulgarian team focused on opening a home for very young children with disabilities, involving their families, and attempting to integrate the children into various community resources (e.g., regular day care or kindergartens). They envisioned that these actions would be guided by a newly established steering committee. They requested that we:

1. *Provide information on the possibilities to those making decisions* and otherwise seeking to develop the envisioned model. Sending videotapes to illustrate similar programs or printed information to inform their discussions would be helpful.
2. *Provide training*, but of two types:
 - a) Information (presented in person) on the front end of things to help Bulgarian participants to gain a clearer vision of their intentions --- to think things through. For instance, they might consider a family support initiative to keep children home in the first place as a nice complement to the home they seek to develop. In fact, family support or supported foster care could be the centerpiece, with the home being a fall

back option.

Also, again the tie to decentralization could be made stronger. What are the roles of local government, service agencies and family members?

- b) Follow-up information related more directly to implementation issues --- service approaches, advice over specific disabling conditions, administrative mechanics including decentralization.
3. *Related requests* were also made for adaptive equipment and overall strategies for mobilizing the community.

After consideration of their requests, in relation to the resources available, we decided to:

- ☆ Compile and send to the Bulgarian team printed information related to their requests.
- ☆ Visit Bulgaria once. Our visit was to focus on providing information on the range of service possibilities, and to facilitate discussion concerning: (a) service intentions, and (b) potential administrative structures, including exploration of decentralization. We planned to focus primarily on services for children with disabilities and their families, emphasizing family support, inclusive education, and other practices to illustrate the merits of approaches that maximize community integration.

We anticipated that our actions will help the Bulgarian team to develop a much needed pilot for young children with disabilities and their families. Again, we hoped that our presence would also be used to encourage their exploration of the potential for collaboration among various levels of government.

Arrival-Departure

John Agosta arrived in Sophia, Bulgaria on 9/16/95, departing for Prague on 9/24/95. During his time there he was joined by David Janner-Klausner of JDC Israel from 9/17/95 to 9/21/95.

Materials Provided

Prior to the visit, materials were sent to Dr. Yadkova of the Ministry of Health. In Addition, while on site other materials were also disseminated. These materials were related to best practices in disabilities services but focused on early childhood services and family support. A list of the materials is as follows:

Agosta, J. & Melda, K. (1995). *Pushing toward community: An account of deinstitutionalization in the United States*. Salem, OR: Human Services Research Institute.

Agosta, J. & Melda, K. (1995). *Supporting Families who provide care at home for children with*. Salem, OR: Human Services Research Institute.

Agosta, J. (1992). *Organizing for change: A guide for families to organize to influence public policy*. Salem OR: Human Services Research Institute

Backyards and butterflies: Ways to help children play together. (Report on social integration for children with disabilities).

Bradley, V., Agosta, J. and Blaney, B. (1994) *A comparative study of decentralization in three Scandinavian countries*. Cambridge, MA: Human Services Research Institute.

Covert, S. (1993). *Whatever it takes: Examples of excellence in family support*. St. Augustine FL: TRN, Inc.

Family Support Program Quality Indicators (produced by the Human Services Research Institute, Salem Oregon).

Ministry of Social Affairs (1994). *Social Policy in Denmark*. Copenhagen: Ministry of Social Affairs.

Ostroff, E. (1995). *A consumer guide to home adaptations for people with physical disabilities*. Boston MA: Adaptive Environments Center.

President's Committee on Mental Retardation (1994). *The national reform agenda and citizens with mental retardation: A journey of renewal for all Americans*. Washington, DC: US Department of Health and Human Services.

Principles of Family Support (Center on Human Policy, Syracuse University)

The Family Support Bulletin (excerpts from several issues, produced by United Cerebral Palsy Associations, Washington DC)

People or Groups Seen

Our stay involved a visit to Stara Zagora, and included meetings with government officials, professionals and parents. Principle MOH staff included Mimi Vitkova, Lazarina Lazarova Yadekova, Tania Tcholakova, Diana Mitsova, Emilija Tasheva, and Galina Petkova Todorova. A list of those we visited with:

9/18/95	MOH staff, travel to Stara Zagora Dr. Herstozova (Stara Zagora Municipality) Drs. Marinova, Kostov, Arnauodova (Stara Zagora Home) Other professionals related to Stara Zagora Home Tour of the Stara Zagora Mother and Child Home
9/19/95	Meeting with Stara Zagora principals (home, education and municipality) Tour of local kindergarten
9/20/95	MOH Minister (Dr. Mimi Vitkova) MOE Deputy Minister (Dr. Dodoz)

	ML&SA Deputy Minister (Dr. Spassova) Representative Union of Disabilities (Mr. Ivkov) JDC - Sophia (Robert Djerassi)
9/21/95	USAID (John Tennant & Lucy Mincheva) Open Society (Villy Raykouska) Meeting of parent groups (10 groups) MOH officials (planning)
9/22/95	MOH officials (planning) JDC - Sophia (Robert Djerassi)

Summary of Results

The Bulgarian Ministry of Health is resolved to reform the nation's response to young children with disabilities. At present, families who keep such children at home receive little or no support. Many, however, are placed out of home.

Children aged birth to three reside in a network of MOH sponsored "Mother and Child Homes." These homes are governed by a medical orientation that generally segregates these children from the community. Aside from serving children with disabilities, the homes also house normal children whose parents cannot provide adequate care and offer shelter to teenage or unwed mothers.

We visited one of these homes in Stara Zagora. We found the staff to be pleasant and caring. However, the home seems overstaffed with medical staff (13 doctors, 131 nurses, 53 paramedical staff) for less than 280 children, many of whom are quite healthy! In fact, the Home's census was reduced by over 100 children last year with no reduction in staff. The Home employs only five social pedagogues and a handful of other educational staff. The tenor of the home is medical. We are told that other homes like these in Bulgaria are similarly run.

After three years of age, children are transferred to homes run by the Ministry of Education and after that to facilities run by the Ministry of Labor and Social Affairs. By all accounts, these other facilities are not so well financed and the conditions are terrible.

The current MOH initiative is a bold one:

- ✓ At the national level they seek to enter into an interagency agreement with the Ministries of Education, and Labor and Social Affairs whereby:
 1. each pledges a commitment to social integration;
 2. children aged birth - ten years can stay in MOH homes;
 3. pilots in three areas will permit children with disabilities to attend regular kindergartens;
 4. regular day care centers will be initiated at the MOH homes; and

5. a national level task force will oversee the effort.

✓ At the local level:

6. pilots in three sites will be initiated, including Stara Zagora;
7. local steering committees will be established;
8. local action plans will be developed that will involve the local ministry representatives, the municipality, schools, mother and child home staff, parents and others from the community; and
9. local actions will stress social integration for children with disabilities and community involvement.

✓ Other dimensions:

10. MOH is working with parent groups and other advocates to gain their input and develop a constituency for the project;
11. MOH is working with MOE to craft new education legislation; and
12. MOH understands that to succeed resources will need to be redeployed or redirected.

The initiative stands a good chance for success. At the national and local levels there is support for the three pilots. At every point we stressed that to succeed they will need to:

- ✓ Craft a consensus vision and mission statement at the national and local level.
- ✓ Craft specific action plans with stated tasks and timelines.
- ✓ Face the need to redirect and redeploy existing resources.
- ✓ Enlist the support of the universities to train reoriented professionals.
- ✓ Train existing medical staff so that they can offer developmental services.
- ✓ Engage local municipalities and the community whenever possible.
- ✓ Enlist the help of parents to support the new agenda.
- ✓ Develop and initiate a "public relations plan" for the project.
- ✓ Work collaboratively to secure additional funds.

In support of these actions, we crafted a prototype Interagency Agreement for the three participating ministries (see **Attachment A**). In addition, our meeting with the USAID office generated several funding possibilities, described more clearly in **Attachment B**, including:

1. Four possibilities involving the USAID: (a) finding a way to tie into a grant program whereby \$50,000 is given annually to selected municipalities to undertake locally defined initiatives, (b) working with the Ministry of Labor and Social Affairs to gain a high priority status on its annual request to USAID for aid, (c) submitting a proposal to a new grants program (set to

begin in October) that will require an NGO to respond, and (d) submit a proposal to the new Democracy Network Project.

2. Submit a proposal to the Open Society Fund, tied to bringing families together from several locations in Central Europe to discuss policy and what parents may do to influence policy.
3. Apply for US Military Surplus through the American Embassy.
4. Apply for funds through the European Union.

Regarding the Military Surplus option, a prototype letter was drafted that could be submitted to the US Embassy (see **Attachment C**). Note that a memorandum was prepared for MOH staff to summarize all our impressions and findings (see **Attachment B**).

Next Steps

Much additional information will be sent to MOH staff, including information on:

- ✓ Public relations,
- ✓ Early intervention curricula,
- ✓ Early childhood testing and screening,
- ✓ Examples of education legislation,
- ✓ Parent newsletters,
- ✓ Community organizing and carepooling, and
- ✓ "Soft Tech" adaptive equipment.

In addition, David and I will seek to send to the Mother and Child Home clothes, toys and specialized equipment.

Overall Impression

The Bulgarian initiative is well aimed and has a great chance for success. Our participation was very much worthwhile, and we think appreciated. We will attempt to continue our modest participation, though this project is ending.

3. Technical Assistance Visit to the Czech Republic

Initial Requests for Assistance and Our Intentions

During the Prague symposium, the Czech team requested:

1. *A written synthesis of research and implementation experiences* on desinstitutionalization from three countries (USA, Denmark and Norway). Issues to cover: (a) pace of the progress made, (b) comparison research regarding differences between those living in

institutions and those relocated, (c) parental attitudes, (d) relative costs for institution versus community services, (e) administrative mechanics for establishing community systems, (f) service delivery models, and (g) relationship to decentralization (if any).

2. *Presentation of the findings* in the Czech Republic with follow-up assistance related to deinstitutionalization.

After consideration of their requests, in relation to the resources available, we decided to:

- ☆ Compile a 20-30 page report to synthesize findings in the United States related to the issues that were raised. The report would rely on existing research and writings. Additional information on the Scandinavian experiences was previously compiled and provided to the Czech team during the symposium, though an additional report was offered during the technical assistance visit.
- ☆ Visit the Czech Republic once to present the information and answer any questions people might have. We anticipated that our stay might also involve a presentation to institution directors and a problem solving focus group including government officials, people with disabilities, advocates, institution directors and NGO staff.

We anticipate that these activities would inform Czech actions to deinstitutionalize services in favor of a community oriented service system. Of course, we expected to explore the potential tie to decentralization, offering input into how district or municipal government can help.

Arrival-Departure

John Agosta arrived in Prague of the Czech Republic on 9/24/95, departing on 9/28. While there he was joined briefly by Bruce Blaney on 9/27.

Materials Provided

Prior to this visit, John had participated in several training workshops in Prague and elsewhere in the Czech Republic. During these events various materials, including text and videos, were distributed pertaining to individualized and family supports, and systems administration.

For this visit, a special request was made. The Czech team participating at the decentralization symposium specifically asked for a report on deinstitutionalization in the United States. Within the context of a decentralization of decisionmaking, the Czechs were interested in how the community services system was established in the United States.

In response, a report was compiled entitled: *Pushing Toward Community: An account of deinstitutionalization in the United States*. The report was sent prior to the visit, translated into Czech (text narrative only; not the appendices) and disseminated. We understand that the report will be sent to all institution directors. A copy of the report is attached as **Attachment D**. In addition, copies of the following were distributed:

Bradley, V., Agosta, J. and Blaney, B. (1994) *A comparative study of decentralization in three Scandinavian countries*. Cambridge, MA: Human Services Research Institute.

Ministry of Social Affairs (1994). *Social Policy in Denmark*. Copenhagen: Ministry of Social Affairs.

Ostroff, E. (1995). *A consumer guide to home adaptations for people with physical disabilities*. Boston MA: Adaptive Environments Center.

President's Committee on Mental Retardation (1994). *The National reform agenda and citizens with mental retardation: A journey of renewal for all Americans*. Washington, DC: US Department of Health and Human Services.

People or Groups Seen

The visit was planned as a vehicle for bringing together representatives of relevant national ministries, municipalities and providers to discuss deinstitutionalization and community systems. Helena Jungova, our coordinator in Prague, and Dr. Jaroslav Hruby of the National Council for Handicapped People distributed invitations and followed with phone calls.

Disappointedly, the full day meetings held on Monday (9/25) and Wednesday (9/27) were not well attended. On Monday, three people attended, representing the Ministry of Health (MOH), the Prague mayors office and the National Council. On Wednesday, these people were joined by a representative of the Ministry of Labor and Social Affairs (MLSA). Representation from this ministry was essential, since it is charged with planning for and financing institutional and community services.

We learned that the MLSA was not enthusiastic about these meetings because they were committed to institutional reform or improvement, rather than to decentralization or community services development.

On Tuesday (9/26) the day was spent visiting with parent groups and conducting a morning training session for a group of social workers on family support. In the evening, another meeting was held with ten parents whose children have severe disabilities and are from 18 - 22 years old.

In summary, the people met with include:

- Jaroslav Hruby (National Council for Handicapped People) (representative on 9/25)
- Thomas Jung (MOH) (9/25 and 9/27)
- Antonin Mezera (Prague mayors office) (9/25 and 9/27)
- Janka Novájivá (MLSA) (9/25 and 9/27)
- Pavel Dušek (National Council) (9/26)
- Marta Dušekova (Parents group) (9/26)
- Group of social workers (9/26)
- Parents group (9/26)

Summary of Results

With regard to people with disabilities, the Czech Republic is fast approaching a crossroads. A key fact concerns the status of the buildings and land that comprise the nations institutional

network. Since 1990, the government has implemented a policy where previous owners can reclaim property that was previously nationalized by the communists. In the case of institutions, a ten year respite was imposed so that landlords could not repossess their property until 2000. But now it is 1995 and several institution directors are requesting funds to construct new facilities. Should the current large congregate care facilities be replaced with a next generation of clones? Or should resources be redirected to promote deinstitutionalization?

Meanwhile, there has been ongoing concern about the present living conditions in institutions. Should resources be used to reform or improve current conditions, or should resources be used to "transform" current institutional structures into ones that more encourage community services? Complicating matters, the preferences of people with disabilities and their family members remain unclear. Given decades of policy to promote dependence, many people with disabilities are uncertain over any future where government may step back from its role as "provider," even if it means greater independence and social integration. Likewise, family members are not knowledgeable of the array of community options that could be available, nor do they understand how to demand that such options become available.

Finally, all of these issues must be considered within a larger conceptual and practical debate over a decentralization of government responsibility and the privatization of services.

In fact, that these and other issues are being discussed openly is a positive sign, especially since the advocacy movement (parents and people with disabilities) has diversified to display a wide spread of views and is gaining strength. Underscoring these actions is the Czech *National Plan to Diminish the Impact of Disability*. This plan, a planning guide and not a law, clearly states a vision for social integration and a series of steps that must be taken by government officials to realize its goals.

Unfortunately, the essential government agency for reform, the Ministry of Labor and Social Affairs (MLSA), has not taken a particularly progressive stance consistent with the National Plan. It has not met the timelines stated in the plan for paving the way for community services. It did not enthusiastically support or attend the meetings held during this visit, noting privately that they are premature given a commitment to improving services in the institutions. Certainly, this goal has merit, but as the National Plan suggests, such action is tangential to the primary goal of developing a viable community system. Toward this end, numerous legal and administrative issues persist (e.g., contracting with NGO's, staff training, rate setting, quality assurance). In light of the coming deadline concerning landlord reclamation of property and the growing demands for community services, MLSA policy seems inevitably at odds with current trends.

Our contribution was to inform the unfolding discussion. The report we prepared, translated into Czech, will be widely disseminated with the hope that it will illustrate that the present MLSA policy course is not the only option. Added to that, our presentations to parents and others have provided them with much needed information, and hopefully the resolve, to enter the policy debate.

In real terms, our hope of making a contribution to the Czech move to decentralize and deinstitutionalize was only modestly realized. Our efforts were inevitably compromised by a lack of a consensus vision for reform based in community and social integration for people with disabilities. We cannot manufacture such a vision, since it must (if ever) emerge from the Czechs alone. Yet the debate over the merit of reinforcing the past versus inventing a new future has begun. We expect that the information we provided and the discussions we facilitated will have contributed to that debate, regardless of its outcome.

Next Steps

Additional information will be sent, as follows:

To Dr. Hruby: Information on the relative costs of community services.

To Dr. Hruby: Report on the service system in Denmark

To Dr. Mezeka: A report on decentralization in Denmark, Sweden and Norway.

In addition, we will contact Charles Mosley, Developmental Disabilities services director in Vermont, to inform him of our September activities. We understand that D. Mosley will be visiting the Czech Republic in November to discuss deinstitutionalization with several institution directors.

Overall Impression

The Czech preference for discussion of deinstitutionalization within the context of decentralized government was well conceived. Unfortunately, a primary proponent of such discussion at the Prague symposium, Dr. Stasny of the Ministry of Health, resigned over the summer. This, coupled with the apparent enthusiasm displayed by staff at the Ministry of Labor and Social Affairs for institutional reform over a transformation to a community centered system, meant that our meetings could not easily have the impact we hoped for. The MLSA is simply not ready unilaterally to push away from institutions and toward community.

In hindsight, two other observations might be made:

- ✓ The lack of enthusiasm by key ministry players for these meetings illustrates the importance of building a joint vision and consensus -- a shared ownership -- for change among essential constituencies. One or even several groups can not carry the entire burden for reform, if other essential groups are not involved. As we reflect on it and look back to the Prague symposium, it occurs to us that the interest in deinstitutionalization and decentralization stemmed mostly from the Ministry of Health and the National Council for Handicapped Persons, not the Ministry of Labor and Social Affairs. The apparent lack of enthusiasm by the MLSA for the topic at the April symposium remained unchanged over the months and we should not have been surprised by their continued lack of interest in September. Yet the MLSA, as the primary funding agent of services for people with disabilities, is ultimately the most important ingredient to the mix. Within this context, we might have taken a different approach to offering technical assistance.

- ✓ An alternative approach, for instance, might have made greater use of the past and ongoing relationships that the AJJDC project had already established in the Czech Republic. Prior to the visit, we might have done more to involve past AJJDC recipients of training to enlist their support and attendance at the meetings and to urge the MLSA to take an interest (e.g., Olga Svestkova of Charles University, Misha Frycova of DUHA, Radka Soukupova who is now a Deputy Mayor of a Prague district, Milan Chab who is director of an institution). Such activity would have helped to build consensus for the importance of the meetings *before* the September visit. And it would have helped to assure a better turnout at the September meetings with an expanded dialog between the essential constituencies. By not building on and utilizing these existing relationships we may well have contributed to the "missed opportunity" we felt.

However, real discussion about deinstitutionalization, community services and decentralization cannot be put off indefinitely. The continued interest of MOH, the National Council for the Handicapped and the mayors office in Prague signals that a community system will inevitably emerge. Moreover, a growing number of advocates (parents, people with disabilities, professionals, community service organizations) will surely swell the interest for a community system. In this regard, the entire AJJDC project which has unfolded in the Czech Republic over the past several years has had and will continue to have a dramatic impact. Happily, these September meetings that we held were not the only activities underway in the Czech Republic to bring about reform in disability policy and practice. The issue at hand seems now to have less to do with whether things will change, but more to do with the pace of change and its substance. To this end, we hope that the discussions we held and the report we prepared will contribute, albeit modestly.

4. Technical Assistance Visit to Hungary

Initial Requests for Assistance and Our Intentions

From our perspective, while attending the Prague symposium, the Hungarian team experienced difficulty over reaching agreement. They were all interested in developing a quality assurance system (monitoring) of some type for NGOs. Some wanted to devise a series of performance standards and then evaluate NGOs. Others did not want to go so far as an evaluation, seeking instead the simple compilation of "indicators." We advised that performance indicators should be devised based in input from relevant constituencies (i.e., people with disabilities, service providers, government officials, advocates and professionals).

The team agreed to meet once more in Budapest around the topic to settle on (a) the purpose of the eventual data collection, (b) the stakeholders, (c) final purposes and timelines, and (d) to tell us what we might do. The team *did* meet as agreed. They were interested in our: (a) sending information on quality assurance, performance standards, and performance measures, and (b) visiting once to present the information and facilitate discussion.

After consideration of their requests in relation to the resources available, we decided that we could:

- ☆ Compile and send to the Hungarian team information related to their requests.
- ☆ Visit Hungary once to present the information and answer questions.

Arrival-Departure

John Agosta arrived in Budapest in Hungary on 9/14/95, about 12 hours later than expected due to a canceled flight from Washington, DC, on 9/12/95. He departed Hungary for Bulgaria on 9/16/95.

Materials Provided

Prior to the visit, various materials were sent to Dr. Lajos Kullmann. And while there, others were also distributed. These materials concerned general topics related to disabilities, but were greatly targeted to concepts related to quality assurance, assessment and performance contracting. A list of the materials is as follows:

Agosta, J. & Melda, K. (1995). *Pushing toward community: An account of deinstitutionalization in the United States*. Salem, OR: Human Services Research Institute.

Agosta, J., Ashbaugh, J., Bradley, V., & Melda, K. (1994). *Performance indicators for California's regional centers for people with developmental disabilities*. Cambridge MA: Human Services Research Institute.

Ashbaugh, J. (1992). *Performance contracting*. Cambridge MA: Human Services Research Institute

Bradley, V., Agosta, J. and Blaney, B. (1994) *A comparative study of decentralization in three Scandinavian countries*. Cambridge, MA: Human Services Research Institute.

Center for the Accreditation of Rehabilitation Facilities (1995). *Performance standards for rehabilitation facilities and community residences*. Phoenix AZ: CARF.

Ministry of Social Affairs (1994). *Social Policy in Denmark*. Copenhagen: Ministry of Social Affairs.

O'Brien, J. & Lyle-O'Brien, C. (1994). *Assistance with integrity: The search for accountability and the lives of people with developmental disabilities*. Madison WI: Wisconsin Council on Developmental Disabilities.

Ostroff, E. (1995). *A consumer guide to home adaptation for people with physical disabilities*. Boston MA: Adaptive Environments Center.

President's Committee on Mental Retardation (1994). *The National reform agenda and citizens with mental retardation: A journey of renewal for all Americans*. Washington, DC: US Department of Health and Human Services.

Quality Indicators for California Community Service Programs (produced by the Human Services Research Institute of Salem Oregon).

Quality Indicators for Family Support Services (produced by the Human Services Research Institute of Salem Oregon).

Quality Indicators for Supported Employment (produced by the Institute on Disability at the University of New Hampshire).

People or Groups Seen

- 9/14/95 Undersecretary of State, Ministry of Welfare (Dr. Boldizsár Bíró)
Center for Retired Health Care Workers (Dr. Baláz Krémer)
- 9/15/95 Foundation Motivation: [Included discussion with Péterme Zalabai (director),
Maria Rupp (university professor), parents and people with disabilities]
- National Institute for Medical Rehabilitation: [Included meeting and
discussion with Dr. Lajos Kullmann (director) and six staff people]
- Siló Services [Included visit to services directed by Dr. Pál Gadó]

Summary of Results

From the start our visit to Hungary was a challenging undertaking given the difficulty this country team had in Prague with gaining consensus over the purpose of technical assistance. The team agreed to a focus on quality assurance and performance contracting related to community private non-profits that deliver human services.

Hungary is a nation of about 10 million people, with 20 countries and over 3,000 municipalities (local councils). There are about 18,000 non-profit organizations offering human services, typically under rather loosely defined terms and with very little complementing information gathering to describe what services are offered, to whom, and at what cost or effect.

In some ways, the issue here is not the need for decentralization, but for a re-centralization of mission and systems organization. Decentralization has occurred so that the number of local NGO's is extraordinarily large, while the national government has no real structure for managing such a diffuse system in terms of its overall mission, services delivered and accountability.

Until recently the national government paid 50% of the cost for the services, with local programs providing the other 50%. Given their investment, the national government had initiated actions to establish a better defined contracting process and information tracking system, including standardized norms for service delivery and payment.

Now, however, the government has scaled back its contribution to 25%, weakening its argument for a standardized tracking system. Yet service providers complain that the government is increasing its demands for information, even as it decreases its investment. The government counters that it seeks information related *only* to the money it contributes.

Added to the mix is the ongoing debate over what constitutes "best practice" in Hungary with regard to people with disabilities. Many past practices that emphasized segregation are coming under fire as alternative community centered approaches struggle to take root. The government supports the new emphasis on integration and seeks to push it along by (a) guiding the contracting process more directly, and (b) setting quality assurance norms that reflect the new thinking.

Service providers do not necessarily disagree with these intentions, but argue that: (a) the government contributes little and so has little ground for demands; (b) the new information demands cost money to satisfy the providers will not be compensated; (c) providers must be included in any decision making that could result in a reformed contracting and quality assurance system. And, of course, people with disabilities and other concerned interest also want to have a say.

It is an exciting time in Hungary. The service system is evolving and most agree that information must be collected to track the present system and guide system improvements. Yet there is an ongoing (and not unusual) tension between the key players (government, providers and consumers).

Regardless of where I spoke or with whom, my intent was the same:

- ✓ To provide information on contracting and quality assurance systems in the United States, including frank remarks on their strengths and weaknesses.
- ✓ To provide information on "best practices" in the United States and on what might be done to encourage system reform.
- ✓ To urge collaboration involving all the essential constituencies.
- ✓ To facilitate discussion on the complementing roles of various government sectors (state agencies and local government) in shaping needed reform.

While we did not establish a concrete project for reform, the information we offered was accurately targeted to their requests. We expect that the information will be used as government officials and providers work to revise the current contracting process, and to develop a meaningful quality assurance system.

Next Steps

Some of those we met with requested specific information. For instance, Lajos Kullmann requested additional information on quality assurance, including discussion of how to balance between accountability and flexibility. Maria Rupp requested information on mainstreaming, full inclusion and carepooling networks. Requests such as these will be honored.

5. Technical Assistance Visit to Poland

Initial Requests for Assistance and Our Intentions

The technical assistance agenda mainly derived from the work of the Central European Centre for Behavioural Economics (CECBE), a foundation represented on the country team by Dr. Juros and Wotek Otrebsky. A significant aspect of the Centre's mission is the "integration of disabled persons in the local community through their social and economic activation." The technical assistance sought was as follows:

1. *To have our team participate in designing and conducting an evaluation of existing demonstration projects initiated by the Centre.* The evaluation would likely focus on the activities of the Centre for Prophylactic and Rehabilitation that is seeking to create a model of integration for people with disabilities in the community of Leczna, near Lublin. The goal of the evaluation would be both to provide useful feedback as well as to promote the visibility and status of the effort, especially to central and local governments
2. *To have our team participate in a Seminar including representation from all levels of government and NGOs.* The goal of the seminar is to educate state, regional and local officials on the potential for the integration of activities on the local level as described by recent legislative acts, with a focus on integrating people with disabilities.
3. *To have our team participate in designing and conducting a teleconference or some national event on best practices in vocational rehabilitation.* One of the CECBE's projects is a Center of Vocational Rehabilitation in which Wotek is playing a leading role. To promote both the Center and the employment opportunities of people with disabilities, Wotek proposed our involvement in a national event on supported employment.

After consideration of their requests, in relation to the resources available, we decided that we could:

- ☆ Provide feedback on the evaluation plan they are devising to assess the process and outcomes associated with the decentralization pilot in Lublin.
- ☆ Interview people (about 5-10 people) involved with the decentralization pilot and lead a discussion seminar on the findings.

Actions in Poland to decentralize are already underway with pilot efforts in place. We anticipated that our presence would help to inform the activities already underway and to provide needed perspective. We decided not to offer a teleconference as was requested, owing to budget limitations. Likewise, while we would have wanted to participate in the seminar, the timing did not work. The meeting was scheduled for September 6-8 and we could not visit Poland until later in the month.

Arrival and Departure

Bruce Blaney arrived in Lublin on September 24, 1995. He departed from Lublin for Prague of the Czech Republic on September 27. On September 28, he returned to the United States.

Materials Provided

Prior to the visit, John Agosta sent by mail to the Polish team a variety of information on decentralization in the United States and on developing community partnerships. While there, these texts were offered:

Bradley, V., Ashbaugh, J. and Blaney, B. *Creating individual supports: A mandate for change at many levels*. Baltimore, MD: Paul H. Brookes Publishing.

Bradley, V., Agosta, J. and Blaney, B. (1994) *A comparative study of decentralization in three Scandinavian countries*. Cambridge, MA: Human Services Research Institute.

Agosta, J. & Melda, K. (1995). *Pushing toward community: An account of deinstitutionalization in the United States*. Salem, OR: Human Services Research Institute.

Ministry of Social Affairs (1994). *Social Policy in Denmark*. Copenhagen: Ministry of Social Affairs.

Ostroff, E. (1995). *A consumer guide to home adaptation for people with physical disabilities*. Boston MA: Adaptive Environments Center.

President's Committee on Mental Retardation (1994). *The National reform agenda and citizens with mental retardation: A journey of renewal for all Americans*. Washington, DC: US Department of Health and Human Services.

People or Groups Seen

The visit to Lublin was hosted by Dr. Andrej Juros, Vice President of the Central European Center for Behavioral Economics and his colleague Wojtek Otrebski. The Center is an NGO that serves as a training and technical assistance resource to the hundreds of NGO's that emerged after the fall of Communism in 1989. Many of these NGO's are arose to support people with disabilities. My visit focused on participating in a two-day retreat under the auspices of the Center to design a five day training process to train professional staff in implementing a newly passed state law, mandating the creation of community services for people with mental illness.

Summary of Results

One dimension of the challenge facing the planners of the training process was that the mental health legislation was ambiguous on the key issues of the commitment to deinstitutionalization as well as the nature and purpose of community-based approaches. Much of the retreat was

rooted in the awareness that the training would be the one substantial opportunity to provide clarity of direction and support design.

Just as in Slovakia, one approach to defining a community-based system drew largely on the institutional model, a continuum of facility-based and segregated services, such as day hospitalization and segregated social clubs. My role as I defined it was to offer a clear alternative to that model rooted in individual supports and social integration. I was able to present for most of the first afternoon on supported employment, supported living and inclusive recreation.

On the second day, the focus shifted to a discussion of personalized planning, the foundation for the design of individual supports. I outlined the process and suggested that the training should support participants in planning outward from individuals rather downward to individuals from the institutional model. In that regard the retreat embraced my suggestion that people with mental illness who currently used services should be invited to each training to tell their stories and demonstrate the "career of mental patient" that is the main option offered by the current approach. The presence of individuals, I emphasized, also roots the development of supports in the aspirations and interests of real people rather than abstractions such as the "mentally ill population."

Next Steps

1. A teleconference with the planning group that focuses on training the trainers in the content, process and uses of person-centered planning.
2. A. Juros and W. Otrebski are seeking to arrange study tour of model projects in the US that demonstrate the individual supports approach.
3. A. Juros is seeking to arrange for the return of B. Blaney to conduct training on person-centered planning and the supports strategy.

Overall Impressions

The Centre's way of framing issues and conceptualizing their mission focuses on creating a policy and legislative foundation for the existence of community services and supports and perhaps even more for the existence of non-governmental organizations as major service providers. According to Center leadership, the central government has become progressively more hostile to NGO's as service providers. The only substantial power base for NGO development, therefore, remains the Catholic Church.

This period is clearly a contested one, pitting emergent NGO's with few organizational skills or human service knowledge against an antagonistic government. In this context, the Centre for Behavioral Economics is a crucial ally and supporter of the NGO sector. Currently, the Centre is trying to ensure the survival of the hundreds of NGO's that emerged after 1990. The training discussed above, for example, centers on fundamental issues of organizational viability, such as proposal writing and financial management. The training is also positioning the NGO's to become recognized providers under the first legislation to mandate community-based services

within the mental health system. The proposals that the NGO's develop will largely seek funding allocated under that legislation.

Given the foundation-building and survival focus of the Centre vis a vis the NGO sector, the major vulnerability, as we perceived it, is that the Centre will define any community service model as better than nothing; such a posture echoes the US non-profit sector in the 1970's in its belief that any service is better than no service. The lessons from that period are that an uncritical services strategy may create more problems that it solves, such as the establishment of institutional models in the community, that are taking years to dismantle.

Our formal participation in the retreat as well as informal conversations with Centre leadership urged that Centre staff, themselves, develop a knowledge base rooted in a critique of the facility-based continuum within mental health and an understanding of individual and natural supports strategies. Such a content, I urged, was crucial to bring to the emergent NGO's, so that they would not wed their organizations to ineffective and expensive service models.

To create a learning context both for Centre and NGO staff, I suggested the creation of pilot projects in individual support to community housing, jobs and cultural activities within several NGO's. Within these pilots the Centre will provide technical assistance in proposal development and follow-up training and technical assistance in support design and implementation. As discussed below, HSRI staff will be available to Centre staff through teleconferencing in creating such learning and demonstration efforts.

6. Technical Assistance Visit to Slovakia

Initial Requests for Assistance and Our Intentions

While in Prague the Slovak team requested:

1. *More information on Norway.* The Slovak team was interested in what they called the "Norwegian strategy" for reform and delivery of services. It was pointed out that Norway relies almost entirely on state-run services, whereas Slovakia intends to rely on NGOs, and so one might question the relevance of the Norwegian model. In this regard the American experience may be more useful, given the reliance in the US on private service agencies. To contrast, Norway decentralized using a "top - down" strategy, an approach that was attractive to the Slovak team.
2. *Review and comment on government reorganization.* The government, with help from some members of the Slovakian country team, is drafting a "framework document" on governmental reorganization, which was to be available by the end of April. The report will include an extensive assessment and description of the current system as an introduction to proposed reforms. The team indicated that they would send us the draft as soon as it is released for distribution. (The document is not yet completed)

3. *Review and comment on the new bill on Social Assistance.* The government is drafting legislation on social assistance that is an attempt to shift the current emphasis on cash subsidies to give at least equal weight to the provision of services. The focal group for the bill are people facing social emergencies, including people with severe disabilities. The team would like us to offer comment and provide relevant documents. The team indicated that they would send us a copy as soon as it is released for distribution. (The bill is not yet completed)

After consideration of their requests, in relation to the resources available, we decided that we could:

- ☆ Review and comment on the Slovak initiative to reorganize government with regard to decentralization and Social assistance.
- ☆ Provide information on the process and outcomes in the United States regarding deinstitutionalization. In addition, such information will be complemented with analysis of the relationship to decentralization.
- ☆ Visit Slovakia once. During this visit we expected to offer feedback on proposed efforts to decentralize social services and reform such services, with some emphasis on implementation issues.

Arrival and Departure

Bruce Blaney arrived in Bratislava on September 19, 1995. He departed from Bratislava on September 23, 1995, heading to Poland.

Materials Provided

Agosta, J. & Melda, K. (1995). *Pushing toward community: An account of deinstitutionalization in the United States*. Salem, OR: Human Services Research Institute.

Bradley, V., Agosta, J. and Blaney, B. (1994) *A comparative study of decentralization in three Scandinavian countries*. Cambridge, MA: Human Services Research Institute.

Bradley, V., Ashbaugh, J. and Blaney, B. *Creating individual supports: A mandate for change at many levels*. Baltimore, MD: Paul H. Brookes Publishing.

Ministry of Social Affairs (1994). *Social Policy in Denmark*. Copenhagen: Ministry of Social Affairs.

Ostroff, E. (1995). *A consumer guide to home adaptation for people with physical disabilities*. Boston MA: Adaptive Environments Center.

President's Committee on Mental Retardation (1994). *The National reform agenda and citizens with mental retardation: A journey of renewal for all Americans*. Washington, DC: US Department of Health and Human Services.

People or Groups Seen

Members of the Ministry of Labor, Social Affairs and Family of the Slovak Republic: The Ministry hosted the visit, members accompanying me on all site visits.

Mrs. Viera Tomanova Director of the Department of Social Welfare
Mrs. Lydia Brichtova, Vice Director of the Department of Social Welfare
Mrs. Kvetoslava Repkova, Department for Social Care
Mr. Andrej Poracky, Department for Social Care
Dr. Anton Blajsko, Department for Social Care

The Ministry structured the visit as a group interview with the above members, followed by two days of site visits to various services and interviews.

Site Visits to Public Services:

9/20 Kamping: A day care facility and week-day residential program for children and adolescents with disabilities: Tour and interview with director.

9/20 The Social Center for the Elderly: Elder Housing: Interview with director, tour and spending time with residents.

9/21 Sheltered Workshop and Day Center for Adults with Mental Retardation: Tour and interview with director.

Site Visit to a Private Service:

9/21 Eight-Person Group Home for Adults with Mental Retardation/Christian League: Interview with staff and a board member, spending time with residents.

Interview with Members of the Parents' Movement

9/21 Meeting with members of the Down Syndrome Society in Slovakia at the home of Mrs. Viola Suterova, president of the Society

Feedback on Impressions and Interpretations of Policy and Service Trends

9/22 Members of Ministry, Invited Service Providers and Members of the Down Syndrome Association attended.

Summary of Results

The goals that I arrived with and refined during the course of the visit were two:

1. To assist the Ministry to clarify the guiding principles of proposed framework policies and legislation, especially regarding the increasingly greater reliance upon services run by NGO's rather than the public sector.

2. To assist the members of the parents' movement in developing a focus for systemic advocacy.

Interpretations/Recommendations to the Ministry of Labor, Social Affairs and Family:

Currently the Slovak Republic does not provide community-based services or supports to people with mental retardation, (the major focus of my site visits) with the exception of one group home and a sheltered workshop/day center for adults and a day care center for children in Bratislava and another group home and workshop/supervised employment center in Bardejov, a town in the eastern part of the country. Up to this point supports have taken the form of cash allowances, such as assistance in buying a car, the largest lump sum available. The Ministry wishes to redress the imbalance between services and allowances, moving toward an emphasis upon services.

The rationale is three-fold:

- ✓ To support families more effectively and therefore begin to decrease the reliance upon the institutional system, now comprising 256 large institutions throughout the country.
- ✓ Some members of the Ministry feel that the use of allowances prevents the targeting of resources to the child with a disability. As one member said, such resources may be utilized by other members of the family. By relying on the provision of services, some feel that services will be more focused on the child with a disability.
- ✓ To address the extensive unemployment problem in the Republic by creating human service jobs. For example the substitution of a transportation service for a cash allowance creates jobs.

Based on site visits and interviews, I concluded that the major issue was what kind of community-based approach the Ministry should develop, especially regarding the design of policies and support models. Currently the focus is on moving toward downsizing institutions by developing large group homes (8-18 people), sheltered workshops, day centers and week-day residential institutions for children. Family support discussions express distrust for families, suggesting that families are incapable of managing the allowances effectively or that using the money for the whole family as opposed to the child with a disability is irresponsible. In addition, the use of a services strategy to solve unemployment unfortunately makes people with disabilities and their families into a means to support the broader society rather than the goal of a social policy designed to improve their lives.

One overarching theme in interviews with all service providers was the complete absence of awareness or effort regarding inclusion in the work, residential, recreational or educational domains of mainstream society. All projects are premised on segregation, from the folklore club for children with disabilities, to the exclusive use of sheltered workshops and group homes to replace the reliance upon institutions. Likewise the service models for family support look to the Champion Center, which is an institution that sends children home on week-ends. There are currently two children in the country with mental retardation who are in regular schools.

In effect the Slovak Republic is repeating the mistakes made by Western Europe and the US in the 1970's and through much of the 80's: It is planning relocate the institutional model to the community. In my feedback I emphasized this theme, showing that the proposed direction, with its commitments to facilities and 24 hour supervision as a rule, was financially not feasible. More importantly the institutional model continued to isolate people with disabilities from both presence and participation in the roles and relationships of the broader society.

Much of the presentation focused on providing specific alternative images and designs that support people with disabilities in choosing and living in community housing, having real jobs, participating in community recreational activities and going to regular schools and day care centers. Regarding family support the message was that the most effective support was support to the enriched life of the whole family and that a focus on disability rather than family had not only not enriched the family but had turned the family into an overburdened source of care provision. This approach is currently described in the US as individual/ family supports to inclusion and has proven to support both social integration and far more cost effective strategy than facility-based models.

Response of the Ministry:

The response of members of the Ministry was divided. Two members were outspokenly enthusiastic, indicating that the choice point between the institutional and the inclusion approach was a subject of ongoing debate inside the Ministry and that my feedback had strengthened those who wished to pursue inclusion. The other reaction criticized my not addressing the choice point between allowances and services, defined by several as the real choice point. I disagreed that that was the choice point, suggesting that a combination of supports and allowances in the interest of inclusion should guide the key policy decisions.

Interpretations and Recommendations to the Parents' Movement:

The Down Syndrome Association (SDS) is the core of the parents' movement in the Republic. Currently it has a small membership, although it did organize and host the 1995 annual meeting of the International League of Associations for the Mentally Handicapped. Members described an environment, both social and political, that was wedded to segregation. They also described themselves as tired. I shared my impressions as discussed above and urged the Association to embark on a small pilot project that could demonstrate the possibility and desirability of inclusion. Members were especially concerned with employment, particularly with current policies that define adults with mental retardation as unemployable.

Reaction of Association Members to Feedback and Recommendations

The response of the Association president following the feedback was perhaps the most gratifying aspect of my visit to the Republic. She said that members had been greatly encouraged by my observations and by their support from some Ministry officials. Association members had decided to design and implement an employment project to demonstrate that people with mental retardation are employable in real jobs in real workplaces and to publicize the project through their newsletter. Their goal was to anchor future policies in that demonstration.

Next Steps

1. A teleconference with parents' association members with B. Blaney and J. Agosta to assist in the design of the employment project.
2. Ongoing contact with officials in the Ministry who are advocating for a supports strategy.
3. Assisting in creating a collaborative relationship between the above officials and the parents' association through teleconferences and the design of the employment project.

Attachment A:

Prototype Interagency Ministry

Agreement for Bulgaria

A Joint Agreement

Between the Ministries of Health, Education, and Labor and Social Affairs to Collaborate on Behalf of Young Children with Disabilities and their Families

Whereas the Ministry of Health, the Ministry of Education, and the Ministry of Labor and Social Affairs agree that:

- The opportunity to participate in fully in all aspects of community life is a right of all members of society, regardless of disability,
- Children belong, first and foremost, with their families, and if this option is not available, then with another family in their home community. Options involving placement in distant communities or in congregate care homes are considered least preferable.
- The health and developmental well-being of children from birth to the age of ten years are to be linked in the best interest of the children
- The future direction for the upbringing of children with disabilities¹ is their physical, educational, physical, and social integration, as much as possible and as the default option, into the communities surrounding childrens' homes
- The future direction for meeting these children's needs shall rely upon a blending together of resources available through the public and private sectors, as well as the informal supports already available in the community through family, friends, non-disabled children, and other caring citizens. Whenever possible actions will be taken to strengthen these informal ties to promote the social integration of children with disabilities.
- This agreement pertains to all children with disabilities, regardless of the severity of physical, mental or cognitive disability.
- The Ministries have differing yet complimentary interests and responsibilities

It is therefore agreed as follows:

GENERAL

- The ministries will embark upon three pilot projects in three locations over the next two years to collaborate in their efforts in the upbringing of children in the care of the state and other children with disabilities who are at home, of which one will be in the city of Stara Zagora
- These efforts shall emphasize:
 - ◊ the importance of families in supporting their children,
 - ◊ utilization of all available community resources, and
 - ◊ collaboration among public agencies to promote an integration of resources to achieve stated goals.
- The ministries will offer their support to the pilot project and create a joint auspices to oversee this effort.

THE JOINT AUSPICES

- The joint auspices will be conducted through a senior steering committee made up of at least three (3) though no more than five (5) officials from each of the three ministries, with the aim of developing a pedagogical program in line with the principals noted above
- The Minister of each ministry named in this agreement shall appoint the specific staff for the Senior Steering Committee.
- Members of the Senior Steering Committee shall elect a chairperson to guide the committee's deliberations. The specific duties of the chairperson shall be decided by the committee.
- The Senior Steering Committee shall prepare guidelines for local projects to follow. These guidelines shall state the overall mission of the pilots, provide a series of framework principles to

guide local efforts, specify what reports will be required of the pilots, and offer a series of concrete examples of the types of local actions that are expected

- The Senior Steering Committee is obliged to:
 - take advice on its decisions from the National Organization of People with Disabilities,
 - report to this Committee, at least quarterly on its intentions, actions and accomplishments, and
 - act as a liaison to local steering committees established at each pilot site.
- Within three months of signing this agreement, the Senior Steering Committee will present a detailed blueprint for collaboration to the Ministers that shall outline the planned actions for the three pilot sites.

THE PILOT PROJECTS

In Stara Zagora:

- A Steering Committee will be established to oversee and guide the pilot project. The committee will include representatives of the three ministries, the locally affected municipality, and other related professionals. At least 25% of the committee will be composed of parents of children with disabilities, with another 25% composed of local citizens that are not directly related to social services.
- This Steering Committee shall prepare a *Plan of Action* that shall articulate:
 - the *Mission* of the pilot project;
 - the *Principles* that shall guide all project actions;
 - the intended *goals and objectives*, including a summary of how these objectives shall be achieved;
 - the intended *outcomes* of the project, including social and financial costs or benefits,
 - the strategy that will be applied to evaluate the project in terms of the effects on the participating children, the satisfaction of family members, associated changes in cost, and any other outcome judged valuable.
 - the strategy that will be used to *disseminate* the project actions and results.
- The Plan of Action developed in this pilot shall at the least include the following objectives:
 - The Mother and Child Home will implement a program where the children who live there will, to the extent reasonable, be integrated into regular classrooms, including kindergarten and beyond.
 - As needed, children with special needs will receive individualized supports and accommodations to promote their participation in the regular classrooms.
 - A special day care center will be established to provide day care services to children with disabilities who live at the home as well as others (for a fee) who live with their families in the community. The center will also serve (for a reasonable fee) a reasonable number of children without disabilities who live in the community.
 - A special family support group will be established so that the family members of children with disabilities can meet regularly to discuss the pilot, their needs and to otherwise offer mutual support.
 - Family members of children participating in the program shall be informed of the project's intentions, and consulted for their opinion over how the project can be improved.
 - A training program will be developed and implemented to provide specialized instruction and technical assistance to -participating staff both at the Home and the classrooms.
 - A training program will be developed with the local university to offer instruction and practicum experiences to university students

- regular reports (about two pages in length) will be prepared quarterly to describe the project's actions and progress. These reports will be sent to the national level Senior Steering Committee and released to the press to publicize the pilot.

The Other Pilots

To be determined, though each will be required to establish a Steering Committee, develop a Plan of Action, and provide the Senior Steering Committee with regular reports. These other pilots need not be identical to the Stara Zagora effort, but should be similar in spirit and intention.

FINANCIAL AND INKIND RESOURCES

It is expected that these pilots are to be conducted primarily through a re-deployment and pooling of existing resources and staff. As part of its detailed plan, the Senior Steering Committee shall specify what contribution in resources (staff and financial) each ministry shall make. These specifications will fit within available budget allocations, though may illustrate a reallocation of existing resources and staff at the state and local levels. The plan shall also illustrate how any cost savings realized from the project shall be utilized, though the Ministers accept that most if not all such savings should be kept by the local pilots.

As warranted and feasible the Ministers may allocate additional resources to facilitate the success of the pilots.

SIGNATURES OF AGREEMENT

_____	_____
Minister of Health	Date
_____	_____
Minister of Education	Date
_____	_____
Minister of Labor and Social Affairs	Date

Attachment B:

**Memorandum Summarizing Our Impressions
while in Bulgaria**

Memorandum

To: All of You
 From: John Agosta
 Date: September 22, 1995
 Re: This and that, and next steps

I think it has been a good week. I wanted to put on paper my impressions along with a description of the next steps you might take. So here it is:

Potential Next Steps

1. Immediate Follow-up. It is important to follow-up quickly on this week's events. The meetings this week have created momentum for your initiative and a level of expectation for change. But it can all evaporate quickly if you take too long to act. You might:

- Write a letter of thanks to those we met with this week. In your letter reiterate your intentions and thank the person for his or her support. You might specify what steps you are planning to take, and add other special notes depending on who you are writing.

For instance, to the Ministry of Education you should specify that you will soon be seeking their participation in a formal Interagency Agreement.

2. Legislation drafted by the Ministry of Education. I do not know what influence you can have. However, Mr. Dodov indicated that they are drafting new legislation. It is essential that the new law contain words that are consistent with your intentions. If not, your pilots will encounter big trouble later. You can ask to have input directly, given your initiative with young children. And you might encourage certain parents to contact Mr. Dodov directly to request that a special Parents Task Force be established to provide advice on the disability portions of the new legislation. He may very well say NO to the first requests, but persistence may win out. This is very important for the long term.

3. Actions Taken within the Ministry of Health. Of course there is much to do. But to keep it all moving, you might:

- Edit the draft Interagency Agreement that David and I prepared so that you are fully comfortable with it.
- Discuss what the other Ministries might say about the agreement and think about what your response will be. Essentially, you want to anticipate their criticisms and be prepared to compromise or offer alternatives. It seems that the Ministry of Labor and Social Affairs can be an ally here and together you can bring the Education Ministry along.
- Send a copy of the draft agreement to the appropriate Ministry offices with an accompanying letter to restate your intentions. Request that an interagency meeting be held to hear opinion and to finalize the agreement.
- Follow with a phone call to set a date for a meeting.

- Don't discount the potential influence of the family groups. If things get bogged down and seem to be going nowhere, they may be organized to help push things along. In fact, you might want to present a draft of the agreement to a small group of families to gain their advice. If they have a say in things at the beginning they will offer stronger support for it later. They will have a feeling of ownership over it that will be helpful.

You might also find a way to involve the new National Council on Disabilities. If they agree with your intentions, they can be most helpful as time goes on.

4. **Stara Zagora.** I could be wrong, but it seems that there is a lot of energy there, yet it is not totally focused as a cohesive mission with an accompanying action agenda. Encourage them to proceed as is described in the draft Interagency Agreement. That is, they need to: (a) establish a local Steering Committee, (b) draft a cohesive mission statement with accompanying goals and objectives, (c) draft an action plan that lists specific tasks, timelines and the party responsible for completing the task.

By the way, you might issue a memorandum indicating that in the new pilot programs the teachers need not wear white smocks, but can come dressed in regular clothes if they want.

5. **The other pilot sites.** When two other sites are chosen, the appropriate people should be contacted and the ball set rolling.
6. **Funding possibilities.** It is clear that that the chances for acquiring new money in Bulgaria for this project are very slim. You will need to find ways to reallocate or redirect existing resources, both financial and human. Such redirection is not often politically popular locally, so you will need to think about it carefully.

This said, there are several other funding possibilities available. As illustrated below, the efforts of several people must be coordinated to have a chance at success. Some of the possibilities:

- **USAID 1.** We understand that several municipalities are allocated 50,000 dollars annually. The municipal councils decide how they will spend the money. Stara Zagora is one of the sites. Dr. Hristozova should be contacted about this. She should find out what the municipality spent the money on last year and get on the agenda for this year's spending. Perhaps a proposal can be prepared that is tied to their Action Plan. They can ask for a portion of the money. Again parents and a broad based local Steering Committee will be very useful. You might also check with USAID to see what other municipalities are on the list. Call Lucy Mincheva at 544 601 or 543 021
- **USAID 2.** The Ministry of Labor and Social Affairs has already given its list of priorities to USAID for next year. On the list was a priority for employment programs for youth with disabilities who are just past school age. You might work with the Ministry to include this initiative under their priority. Since you are ready to go and have an draft Interagency Agreement, you might be able to work something out with your friends there.
- **USAID 3.** A new grants program will begin in October. We know little about it, but the contact person is Aaron Bornstein at 808 488 or 816 019. His address is at 47 Gvrko Str (6th floor). Call to see what the process is.

- **USAID 4.** There is Democracy Network project underway; the purpose is to strengthen NGOs around civic responsibility, the social safety net, economic development and empowerment. Your project fits **ALL** these categories. I am not certain, but this might be the same as the one Aaron Bornstein is running; Ask him. In this case an NGO must apply. If Aaron is uncertain, you might call back Lucy at USAID to ask about it.
 - **Open Society.** We met with the Open Society Fund. They indicated that they would accept a short proposal (3 to 5 pages) to bring parents together from different countries (Czech, Slovakia, Poland) to discuss how they could influence change in their countries. Parents must apply. I have parent contacts in these other countries and I can offer them to you. Call Vili Raykovska at the Open Society Fund for more information and guidance at 65 03 88.
 - **Union of Bulgarian Foundations.** This Union helps organizations to find money. They can help to write proposals. Call Kamen Lozev at 46 72 41. This fellow volunteered to coordinate the parent groups in a fund raising and public relations efforts, as well as to organize their efforts. You should call him and take him up in his offer and see what happens.
 - **US Military Surplus.** You can submit a letter to the US Embassy to detail your request. The contact is Commander Hassett and his phone number is 884 801 EXT 456. I have provided a draft letter and list for you to send.
 - **European Union;** I am not certain of this possibility, but you should encourage Dr. Hristozova in her efforts in Stara Zagora and see if you can apply for additional EU resources.
- 7. Public Relations.** You should prepare an information packet on the initiatives. The contents are specified elsewhere. Consider how you might proceed strategically in utilizing the media to shape public support and to credit various people. For instance, on the day that the three Ministers sign the Interagency Agreement you might call a press conference to announce the signing. Important people like to see their pictures in the paper or on television. Aside from sending a public message, you will also tie the ministries into the project a bit more tightly.

In this regard, you might contact Robert Djerassi at JDC in Sophia for assistance. He understands how to put together a public relations strategy. His number is: 814 456 or by mobile phone at (0799) 30 816 or 31 884

- 8. Playgrounds.** I know we seem stuck on this idea. But it has great potential for bringing people together. David will send a useful video tape and I can send some design ideas. The rest will be up to the local people to do.

By the way, the last thing our car driver said to me was: "When do we start on the playground in Sophia?" You might take him up on his offer and tie him into some parents and the Sophia Mother and Child Home. Show him the video that David will send and set him loose with these parents. I think he has a gift for making this kind of idea work. Plus, having him work on a playground could keep him out of his car and off the streets, a potential public benefit.

- 9. Future professionals.** We understand that the training of future professionals is a

there is so much more to do. Try to assure that word of your vision and actions reach university students. Guest lectures at the university will be useful at the least, though an entire course on the topic would be best.

10. Other Observations.

- The Ministry of Health can not be expected to do it all. Whenever possible the responsibility for achieving a task should be passed along.

Always act to expand your circle. Have the car driver build a playground in Sophia. Have another sketch out a public relations strategy. Have another work with parents to raise funds that are targeted to the project. Among the family groups we met with in Sophia there seemed to several people who would participate. Eventually, they can provide information to students, issue press releases, educate various policymakers and so forth. Build a constituency for the effort that pushes well beyond the Ministry of Health.

- Pacing and sequencing will be very important. You can get overwhelmed quickly, especially since you have other professional responsibilities to attend to. If possible you might assign a specific person the responsibility of acting as Project Coordinator. In that way you can be assured that this one person will be tracking everything and can sequence events properly.
- It seems that policy decisions that bring people together in ways that promote collaboration and mutual trust is good policy. Decisions that drive people apart or place one against the other is bad policy. In so many ways the initiative you are pursuing is good policy.
- Remember always to have fun with all of this.

What More David and I Can Do:

Of course we want to do a lot, but our wants totally exceed our budget. Certainly we will send information, videos, examples of education legislation, examples of brief grant proposals of the type you must write and so on.

We will try to locate an ultrasound device, though I am not certain of the potential for success.

We will try to gain donations of toys, children's clothes and adaptive equipment.

And we will try to secure additional funds to offer needed technical assistance and training.

Information Packet

An Information Packet should be assembled to describe you intentions. The packet could be used to publicize the pilots, educate legislators and to otherwise document the pilot efforts.

The packet should include the following:

- A statement of the Pilots mission and Goals
- A statement of the orientation or philosophy of the pilots. Perhaps a list of guiding principles will be sufficient
- A copy of the Interagency agreement or a description of its essential elements.
- A description of each pilot, including the goals and objectives.
- Proposals for staff training and university involvement
- A press release on the Project

Attachment C:

**Prototype Letter to Request Surplus
Equipment for Bulgaria**

September 22, 1995

Commander Hassett
United States Embassy

Sophia

Regarding: Donation of Humanitarian Assistance

Dear Commander Hassett:

We are initiating a new project in Bulgaria for young children with disabilities and are requesting a donation of needed equipment.

In Bulgaria many children with disabilities do not live at home with their families, but in a large residential care homes. Typically, these children do not receive the early education and training they need and are segregated from other children in their community. Those children who remain with their families receive little, if any, support as well.

We intend to change these conditions. Three national ministries (Health, Education, and Labor and Social Affairs) are drafting an interagency agreement to promote the social and educational integration of these children so that they may receive the support they need to participate in their communities for the long term. In addition, we plan to initiate three pilot programs that will involve the local participation of existing Mother and Child residential homes, the municipalities and local citizens. It is agreed that these children will attend regular kindergartens and classrooms along with the supports they need. Further, at each Mother and Child Home a special day care center will be established and opened to children in the local community, including those with and without disabilities. At the same time, we want to introduce new educational programs into the residential homes to complement the existing medical orientation.

The local sites of these programs include the Mother and Child Homes in Sophia, Stara Zagora, and Blagoevgrad. Another site in Varna is also under consideration, and at the least could act as a distribution point for any equipment you offer us that is delivered through the Black Sea.

To succeed we need your help. What follows is a list of the type of equipment we need. If you have any questions about our request, please contact me. And if we are fortunate enough to receive any of the equipment we request, you can contact my office and we can arrange for its delivery to the appropriate Mother and Child Homes.

Sincerely,

Dr. Mimi Vitkova
Minister of Health

List of Needed Humanitarian Assistance

Ministry of Health, Bulgaria
Contact: Dr. Lazarina Lazarova Yadkova
359 87 53 19
359 80 00 31 (fax)

September 1995

- 4 Vehicles (preferably mini vans to transport children)
 - Toys of all kinds for infants, and for kindergarten and elementary classes
 - Clothes for young children aged birth to ten years
 - Playground equipment
 - Physical therapy equipment (special toys or devices for positioning, eating...)
 - High chairs for feeding young children
 - Mats that can be laid on the floor for children's play, exercise and rest
 - Wheelchairs
- 4 Portable Ultrasound devices to monitor pregnancies
- 4 Bicycle ergometers with monitor to track ECG, pulse and respiration
- 4 ECG machines (electrocardiograph)
- 4 Electromyographs
- 4 Tangentors

Attachment D:

Full Text of:

*Pushing Toward Community: An account of
deinstitutionalization in the United States*

(Prepared for the Czech Republic)