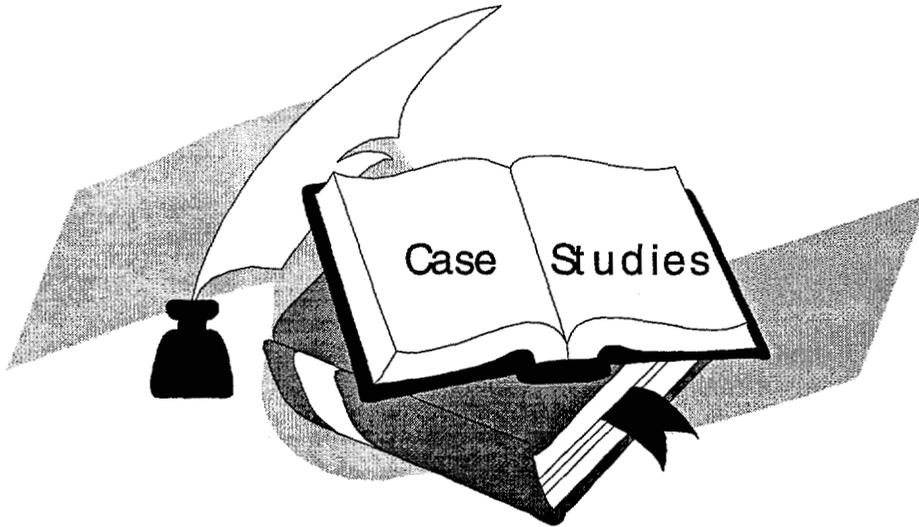


## Appendix II



Final Report to  
the United States Agency for International Development  
of the  
Private Voluntary Organizations Initiatives for the Newly Independent States Project  
World Learning Inc.  
1992 - 1997

**ALCOHOLISM AND RUSSIA: Then and Now**

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The PVO/NIS Project  
June, 1997

## *Alcoholism and Russia: Then and Now*

*The PVO/NIS Project of World Learning, a USAID funded project designed to promote the non-profit sector through partnerships between Western and NIS-based non-governmental organizations, funded 13 health-focused programs in its last round of solicitations. Of these 13 projects, three devoted some or all of their energies to the problems of alcohol abuse in Russia. The project will come to an end June 30, 1997.*

By focusing on alcoholism and addiction, the PVO/NIS Project takes on a non-traditional health topic that very well may be the largest cause of health and economic problems in Russia. Alcohol abuse and chemical addiction, while often the target of public health campaigns in the US, Canada, and Europe, does not usually fall under the realm of international donor concerns outside of these regions. The reasons behind this are unclear, but may reflect a perception of urgency around other health issues in the non-Western world. Nonetheless, alcohol abuse is a well-documented problem across the world, and especially in Russia. As early as the 1840's, temperance societies and other organizations focused on alcohol use and abuse were being formed throughout Russia as a response to the growing spectacle of public drunkenness<sup>1</sup>. In 1904 in Saint Petersburg, 77,901 persons or *six percent* of the total population had been put through police run detoxification centers<sup>2</sup>. Soviet statistics, while noteworthy in their lack of reliability, still reluctantly demonstrate the widespread problem. For example, after examining the available data, one Western scholar concluded that in 1973, 9.5% of the Soviet population (that is to say, approximately 17 million persons) 15 years and over had were considered alcoholics<sup>3</sup>. More recent, post-Soviet statistics suggest that the problem has not gone away. According to USAID, in 1991 there were 1887 alcoholics per 100,000 population (nearly 2 percent of the adult Russian population) in Russia in treatment (as opposed to 155/100,00 population in the United States)<sup>4</sup>. While at first glance this number seems an improvement on earlier numbers, it only reflects those alcoholics actually being treated in Russian detoxification centers and thus greatly underestimates the extent of the problem in Russia.

But why should alcoholism and chemical dependency be considered a social or economic issue, as opposed to merely a private problem for the addict? Well, consider the ramifications for public safety when it comes to crime statistics. Again, according to USAID in 1991 Russia<sup>5</sup>,

- 34% of all crimes were committed by persons intoxicated by alcohol;
- 71% of all murders were committed by persons intoxicated by alcohol;
- and 68% of all sexual assaults were committed by persons intoxicated by alcohol.

These numbers only reflect the impact of alcohol on the crime rate in Russia. Consider what is known about the effects of alcohol use and abuse on the general public in the United States:

- Because alcohol loosens inhibitions and impairs judgment, it has been implicated in unprotected sexual intercourse, which can lead to higher rates of unwanted pregnancy and sexually transmitted infections including HIV/AIDS. Indeed, one national study suggests that adolescent girls who drink at least five times a month were 1/3 less likely than their non-drinking counterparts to use a condom during intercourse<sup>6</sup>;
- Annually, between 16,548 and 22,064 children are born each year in the United States exhibiting the effects of prenatal exposure to alcohol. Approximately one half to one third of these children suffer from Fetal Alcohol Syndrome<sup>7</sup>;
- Women who abuse alcohol during pregnancy also have higher rates of spontaneous abortion and still birth, premature delivery, and low weight and low sized babies<sup>8</sup>.
- Of all fatalities resulting from automobile crashes in 1994, 32% involved drivers or non-passengers (pedestrians, cyclists, etc.) who were legally intoxicated. An additional 8.6% involved drivers or non-passengers with a blood alcohol content between 0.01% and 0.09%, that is to say not legally intoxicated, but not legally sober either<sup>9</sup>;
- One survey of 1200 American couples revealed that of those in which the husband drank excessively more than once a week, 70% of these men physically or mentally abused their wives<sup>10</sup>;
- 74% of college students in one large scale survey who admitted having committed rape, committed the crime under the influence of alcohol<sup>11</sup>.

Clearly, every person infected with an STD because they were intoxicated; every child born to an alcoholic parent; every woman battered by a intoxicated husband; every person killed due to an intoxicated driver or pedestrian is an economic and spiritual cost. American municipal and federal budget statistics agree with this assessment. The following statistics add chemical dependency into the brew, but still demonstrate this statement:

- In New York City in 1995, 77% of children in foster care came from families afflicted with alcohol and drug abuse. In the same study, 77% of reported child abuse cases were also linked to alcohol abuse and chemical dependency<sup>12</sup>;
- In 1995, 18% of US federal spending for health benefits to veterans was due to the effects of alcohol and substance abuse<sup>13</sup>;
- In 1991, 14.8% or 13.2 billion dollars of all inpatient hospital costs for Medicaid were directly related to alcohol and substance abuse<sup>14</sup>.

On their own, American statistics demonstrate how costly alcohol abuse and chemical dependency can be, both from a personal and from a financial perspective. However, Russian statistics, while harder to access than American statistics, also offer a picture of the physical, emotional and economic costs of alcoholism. Consider the following:

- According to Alexander Nemstov of the Alcohol Policy Center in Moscow, in 1996, 50% of men and 30% of women in Russia between the ages of 30 and 50 have experienced liver problems due to alcohol poisoning<sup>15</sup>;

- Furthermore, in 1994, there were 400,000 deaths of Russians due to alcohol poisoning, either from over consumption or from adulterated products. This figure suggests that 61% of all poisonings were due to alcohol<sup>16</sup>;
- Alcohol abuse is implicated in 50% of all suicides and driving accidents in Russia<sup>17</sup>;
- The leading cause of death for all Russians is circulatory diseases. The second leading cause of death is injuries and poisonings -- both of which have been demonstrated to be severely exacerbated in Russia by alcohol. This category includes suicides, murders, driving and other accidents, cirrhosis of the liver, poisonings, and drownings<sup>18</sup>;
- If causes of death are looked at through another tool -- that of Potential Years of Life Lost or causes of premature death, than *47% of premature deaths in Russia in 1994 were caused by injuries and poisonings, making this the leading cause of premature death*. This figure cuts across gender, geographical, and economic distributions<sup>19</sup>;
- This statistic can be explained in yet another way. Currently, the average life span for a Russian male is 57.7 years. This is a considerable drop from 63.8 years in 1990. Most of the excess mortality is for males aged 40 to 44<sup>20</sup> -- not children and the elderly, who are traditionally considered vulnerable groups. Alcohol is strongly implicated in this imbalance of mortality, as it has been linked to circulatory diseases such as heart disease, stroke, diabetes, and some cancers;
- Research shows that in 1993, 25% of Russian boys aged 15-17 drink frequently, or at least twice a month. Some researchers suggest that this figure is too low<sup>21</sup>.

These numbers paint a picture that suggests that the problem of alcoholism and chemical dependency has extreme implications for the health and well-being of all Russians, not to mention the economic prosperity of Russia itself. While it is difficult to assess days lost, or rubles mis-spent, if men and women are dying, or losing their jobs, or being so physically incapacitated by alcohol that they are causing themselves permanent disability, or are abusing their children and each other, than they cannot contribute to a civil society and cannot care for themselves and their families. Indeed, they become a burden on the state on each other, and inhibit the growth of their county.

So what is to be done? Russian modes of treatment for alcoholism usually focus on the moral wrong of alcoholism, and do not recognize the physical and biological aspects of addiction. Coding, forced Antabuse, hypnosis, aversion therapy, and punitive measures such as mandatory stays in psychiatric hospitals are standard forms of treatment. Further, detox centers within the psychiatric hospitals are usually large and have as many as 1,000 beds. The largest detox center in Moscow has 5,000 beds (a large Western center would have at most 80 beds)<sup>22</sup>. Alcoholics Anonymous (AA) was introduced into the then USSR in 1986 and is slowly growing in acceptance. However, anecdotal reports from PIRE/Salus suggest that many of these meetings have been led and run by traditionally trained Russian narcologists who continue to employ an authoritative, punitive manner to guide meetings, and do not allow AA members to "own" the meetings.

What is needed is a new set of tools to deal with the problem. Access to appropriately trained counselors and better treatment programs treat alcoholism as a disease and not a moral failing; successful media campaigns demonstrating the ill affects of alcohol abuse and what can be done to combat the problem; government policy changes and legislative decisions that reflect the understanding that alcohol use and abuse hurts Russian society; are all such tools that can be used together to deal with alcoholism and chemical dependency pro-actively. And this is where the PVO/NIS Project has been particularly successful. Two partnerships --between Gundersen-Lutheran Hospital and the Dubna Educational Center and between PIRE and Salus -- have been aimed specifically at developing networks of alcohol and chemical dependency professionals trained in Western models of treatment. Another -- the CECHE/Association of Physicians on the Don and Health and Environment Foundation partnership -- has chosen to work at the problem exclusively from a media campaign/policy perspective. Together, these three partnership initiatives are developing a network of interested Russians determined to combat alcoholism/chemical dependency and its effects.

### **PIRE/Salus**

In 1988, Mary Kay Wright gave a series of lectures in Western concepts of addiction and addiction recovery in Moscow. Ms. Wright was intrigued and troubled by what she saw in Moscow, and in 1989 approached PIRE with the idea of developing a year long training program for humanistic addiction treatment in Moscow. As stated earlier, until that time, Russian approaches to alcoholism were punitive at best, treating the disease as a moral failing and not as an illness. This training evolved into the Salus International Health Institute, an NGO committed to bringing the concept of humanistic approaches to addiction to Russia and the NIS. This humanistic approach uses the 12 step program integral to most modern Western approaches of treatment and takes into account the biological, psychological, social, spiritual, and family factors of alcoholism and addiction. It does not see the alcoholic as a lone figure affecting and affected by only him or herself, but rather as one in the center of a number of interactive relationships that are all affected by and are affecting the addict. Within three years, Salus with the cooperation of Narcology Hospital #17, began the Recovery Treatment Center -- the first private, voluntary, anonymous treatment unit with Western-trained staff in Moscow<sup>23</sup>. Along with training and treatment, Salus also offers a resource center for research, training, and recovery information, and develops public awareness about the identification, treatment and prevention of addictive disorders in Moscow.

In 1994, the PIRE/Salus partnership won a World Learning PVO/NIS Project grant to develop a Russia wide network of treatment professionals trained in the bio-psycho-social-spiritual model of addiction and addiction recovery. Salus would continue to provide humanistic treatment for alcoholics in recovery at the Recovery Treatment Center, but now it would be able to do even more for those in recovery across Russia. This grant would greatly expand the number of addiction professionals across Russia exposed to the bio-psycho-social-spiritual model of addiction; create the setting for a network of treatment centers with a humanistic approach to recovery; focus public

attention on idea of alcoholism as a disease across Russia through media attention on the trainings; develop a network of Russian addiction trainers able to provide trainings on their own in this model; and further develop the NGO Salus International Health Institute as an authority and resource on humanistic approaches to alcohol and chemical dependency treatment. It would also continue the process of change of how alcoholics and their families are treated by health professionals and Russian culture as a whole. The trainings fell into three types:

- Training of Trainers -- a one year long twice weekly series of classes concerning how to train other professionals in the bio-psycho-social-spiritual approach to recovery. These classes were delivered to extremely committed addiction professionals already trained by Salus through the Recovery Treatment Center.
- Basic Trainings -- week long, forty hour trainings concerning Western concepts of alcoholism, addiction, and recovery offered to Russian citizens involved in or interested in non-Russian approaches to alcoholism by a team of American and Russian addiction professionals. These trainings often included demonstration AA meetings, role plays, discussions of children and addiction, discussions of addiction and the workplace, and a demonstration intervention.
- Advanced Trainings -- month long, 160 hour trainings for those who had completed the Basic Training and wished to further their understanding and counseling skills.

Their efforts have been more than successful. To date:

- Twenty-one Russian addiction professionals have successfully completed the Training of Trainers program;
- 253 addiction professionals in Novosibirsk, St. Petersburg, Moscow, Chita, Azov, and Nizhny Tagil attended the week long Basic Trainings, ten of which have been held;
- 79 of these professionals attended month long Advanced Trainings in Moscow, Novosibirsk, and Chita and will be offering humanistic treatment for alcoholics and addicts in these regions. There will be an Advanced Training in St. Petersburg in the near future, bringing the total number of Advanced Trainings under this grant to four;
- The training of trainers trainees led sections of all Basic and Advanced Trainings and ran all sections of the last few Basic Trainings and the last Advanced Training;
- Three outposts of Salus Treatment Center have been started in St. Petersburg, Chita, and Novosibirsk. St. Petersburg was not on the original grant proposal, but because of the overwhelming response to the Basic Training offered there, was added to the list;
- Press conferences concerning alcoholism and recovery have been held with every Basic Training outside of Moscow, which has been usually followed by a series of newspaper articles concerning Salus and alcoholism.

So far, the feedback has been exciting and indicates that these trainings are welcome and necessary for the future of Russia. By choosing to train trainers, and then provide training across Russia, the PIRE/Salus partnership is succeeding at a daunting task -- to reform attitudes and treatment for alcohol and chemical dependency on a wide scale.

And, they have appeared to have begun to make strong inroads. Each report from Salus has included information from the training evaluations, and suggests that participants in Basic and Advanced Trainings not only begin to understand alcoholism from a different point of view, but that they also begin to re-evaluate their whole perspective on cultural and personal norms regarding alcohol and its use and abuse. In early 1997, the Soros Foundation approached Salus to conduct a Basic Training in Kyrgyzstan and Belarus, and Salus is looking into ways of creating continual sources of fee for service patients. One idea that they are pursuing is to start the first Employee Assistance Program in Russia. This would be paid for by the large employers in Moscow such as MacDonaldis, American Express, etc., and would accomplish two important goals: one, it would provide a continual, sustainable source of funding for Salus, and two, it would provide treatment resources for alcoholics and their families regardless of their ability to pay.

### **Gundersen-Lutheran Hospital/Dubna Educational Center**

Gundersen-Lutheran Hospital, formerly Lutheran Hospital-La Crosse Hospital began its involvement in Dubna, Russia through the Sister Cities program and the AIHA partnership program in 1992. Dubna is a town of approximately 64,000 on the Volga River in the Moscow Oblast. It is one of several Soviet planned "science" cities, and is known primarily as the site of the Joint Institute of Nuclear Research. Under the Sister Cities and AIHA programs, Lutheran LaCrosse Hospital and city health officials identified a number of health issues as priorities in Dubna, including alcohol and chemical dependency. Initial work done to deal with this issue included the establishment of AA meetings in Dubna in 1993 and Al-Anon meetings in 1994; the organization of student clubs against alcohol; and the presentation by American trainers of Western alcohol treatment concepts (based on the same precepts as treatment provided by Salus trained professionals) in a variety of public and private settings in Dubna.

In 1994, Lutheran Hospital La-Crosse partnered itself with the Educational Center of Dubna and won a PVO/NIS Project grant. What made this grant different from earlier efforts by Lutheran Hospital La-Crosse was multi-fold:

- For the first time, NGO development with an identified NGO would be included as an integral part of the grant;
- It would provide consistent, regular training in humanistic based treatment and recovery for alcohol treatment professionals, with monthly review sessions, sometimes under the supervision of Western trainers;
- Media events concerning alcoholism and addiction would be a regularly occurring part of the project agenda;
- It would create a replicable model of training in alcohol and chemical dependency and its treatment that would be used simultaneously in three other towns within the region;
- A large number of Russian alcohol treatment professionals would be brought for training to the United States. In the process, they would be able to see first hand how these models of treatment can work and be effective.

Lutheran-Hospital LaCrosse more than met expectations from the original grant proposal. In the 29 months of the partnership grant:

- 10 government officials from the Dubna region visited LaCrosse, Wisconsin for one week to study how an effective alcohol treatment and media campaign can work in conjunction with local governments;
- Two additional cities requested and were granted the opportunity to join the original four model cities, raising the number of sites directly affected by the project to six. These two new sites, Klin and Zaprudnia, have in some ways been more successful than some of the other sites because of the municipal enthusiasm for the project.
- Thirteen addiction professionals were brought to LaCrosse, Wisconsin for a six-week hands-on training in Western concepts of treatment and recovery for addiction in June-July, 1995. These professionals represented all six project cities and became the nucleus of the Russian alcohol counselors for the project;
- Seven of these professionals returned in June, 1996 to participate in further detoxification training;
- 9 visits to project sites were made by a team of American professionals to observe monthly meetings and to give feed-back and additional training to the Russian team of professionals;
- 136 addiction professionals attended the annual project conference in September, 1995 in Zaprudnia. In September, 1996, 152 addiction professionals representing 15 cities (many trained by Salus) attended the annual project conference in Dubna. These conferences solidified the network of Western trained addiction professionals across Western Russia.

The above statistics only demonstrate the success the partnership has had in training and maintaining the excellence of its Russian alcoholism professionals. Training, however, is useless without evidence that the training has been utilized successfully. From July, 1995 to March 31, 1997 the end-date of the grant, the Russian partner has

- provided 128 community presentations to nearly 18,000 individuals about alcoholism, addiction, treatment, and the like;
- submitted 197 articles for publication in local newspapers concerning the issue. These two statistics are important because they reflect a well organized, consistent plan on the part of the addiction centers to bring media and public attention to their efforts and to the fact of alcoholism in general;
- established regular AA and Al-Anon meetings in all six cities, and Alateen meetings in five out of the six sites. All of these meetings have been led by Western trained counselors and thus avoiding some of the pitfalls of other, less successful groups in other parts of Russia;
- treated an average of 368 clients per quarter at their sites in individual counseling sessions;
- seen 188 persons attending AA meetings and individual therapy sessions newly sober for at least six months;

- been so successful, that the Russian partner in Dubna has been asked to develop a curriculum for the university in Dubna on chemical and alcohol dependency treatment that will be used for all psychology and psychiatry students.

Finally, as of April, 1997, five of the six sites had a commitment from the municipal governments to continue to pay the salaries of all alcohol treatment personnel and to continue to provide adequate space for the established Alcohol Centers for at least one year after the end of the grant. And, after repeated requests for information from other alcohol and addiction professionals looking to work in Russia, Gundersen-Lutheran Hospital has put together a booklet, outlining the "Dubna model". Gundersen-Lutheran is looking to continue its support for this program through its current grant with AIHA, and through an application for a Rotary International grant. However, they have already demonstrated that projects such as this can be sustainable, given an appropriate American partner with strong, regular support and mentorship of its Russian partner.

### **CECHE/ADP/HEF**

The Center for Communication, Health, and Environment, formerly the Central European Center for Health and the Environment began its work in Russia in 1994, with its partnership with the Health and Environment Foundation in Moscow and the Association of Physicians of the Don in Azov in South Western Russia. These two regions are twenty hours apart by train, or a 3-4 hour plane ride. The original goals of this partnership were purely organizational; that is to say, the only tangible goals of the partnership were to develop these two NGOs into leaders in their fields and in the process, develop a loosely knit network of other health-oriented NGOs that would influence health policy in Russia. Thus, the original focus of this partnership was very different than the two previously discussed. This non-service delivery focus also reinforces how truly non-traditional these PVO/NIS health grants were.

In the course of the twenty seven months of the partnership, a service-delivery aspect of the project developed. The two Russian partners -- HEF and ADP indicated that along with substantially developing their organizations and a coalition of other public health organizations, they also wished to focus their efforts on four specific health issues they saw as important to the betterment of Russia and her people. After the first meeting of what became known as the Nucleus NGO Network, both groups felt that alcohol abuse was one of these issues that needed to be addressed. Each NGO chose to address this issue separately and together, and in the process began to develop a comprehensive *public policy* focused approach to dealing with alcohol abuse in Russia. In the process, HEF decided to reform itself into the Russian Public Health Association (ROZA) and thus become a member of the World Public Health Association.

Much of what ADP and HEF/ROZA has been able to accomplish through their efforts to influence public policy has been in no small part due to the intense training received in the United States and on an on-going basis in Moscow and Azov through their partnership with CECH. This training has focused on concepts and strategies, important

to the future sustainability of the organizations and to the NGOs' desires to focus on advocacy and public education. Nevertheless, the impetus for the public policy activities have come strictly *from the Russian partners* -- not the American partners, and thus truly belong to the Russian partners.

These accomplishments are admirable. ADP has initiated a local Alcohol Policy Program with the Azov City Government. Through this program,

- a series of regional seminars focused on training teachers and other professionals in alcohol prevention and narcotic dependence have been implemented;
- a mass media campaign using television programming and print information distributed through ADP's newsletters and other mechanisms has been developed;
- ADP and the City government of Azov are creating an educational video-information center for adolescents that will focus on alcohol abuse and use;
- the City Administration of Azov has been persuaded to restrict the sale of alcoholic beverages on holidays;
- two underground illegal alcohol production operations have been eliminated, following a resolution by the City of Azov to more actively pursue legal action against such alcohol activities;
- the third Nucleus Network Seminar hosted by ADP and HEF was held in Azov and focused on anti-alcohol activities in the different regions of Russia and Europe. The seminar was covered by local television stations, and a press release was published explaining the goals of the Alcohol Policy Program.

HEF/ROZA has been equally successful. To date, HEF has distributed its policy report "The Alcohol Situation in Russia, 1981-1993" to over 1,000 individuals and organizations, including health-oriented NGOs, government agencies, foundations, research and healthcare organization throughout Russian and abroad. This is one in a series of health policy bulletins entitled "All for Health, Health for All in Russia". This particular report has been so popular, that the report and a brochure based on the report are being reprinted. Further, in the summer of 1996, HEF/ROZA received an independent grant from USAID for an eight month program "All-Russia Public Health Policy Forum: Alcohol and Health". This grant of \$43,348, which overlaps with the end CECHE partnership grant, has

- set up series of small advisory committees which met to formulate recommendations on the monitoring the quality and safety of alcohol products, policy decisions that affect the social factors of alcohol abuse and the role of NGOs in the prevention of alcohol abuse. These recommendations will ultimately be submitted to the Russian Duma;
- held an All-Russia Conference on Alcohol and Health in December, 1996 focused on discussing the recommendations of the advisory committees and the implementation of various government and non-government sponsored prevention activities. The recommendations were presented at the conference in the form of a book. This

conference was attended by NGOs, professionals in alcohol abuse, and legislative decision-makers, as well as members of the media;

- will publish the recommendations and materials from the All-Russia Conference by February, 1997 and distributed to appropriate ministries within the Duma, NGOs, the media, and the general public. Other background papers will be published as well that are focused on topics such as trends of alcohol consumption, the impact of alcohol consumption on women, children and the family, and the experience of NGOs in alleviation of alcohol related problems, among other.

The activities and accomplishments of HEF/ROZA and ADP have been watched carefully by other groups, notably, USAID, Abt Associates, the Civic Initiatives Program, and the Canadian Public Health Association. These groups have rewarded the energies and efforts of the Russian partners by providing them with grant monies that have contributed to the groups future sustainability. This in turn, will insure that HEF/ROZA and ADP will be able to continue working on the issues that they hold so dear.

### **Conclusions**

Alcoholism and alcohol abuse is without a doubt one of the biggest obstacles to the future of Russia and her physical, economic, and social health. A concerted cohesive effort on the part of groups and individuals from all parts of Russian life is necessary to begin to change the current reality of alcohol abuse in the Russia. These groups and individuals include the media, federal and municipal governments, health care workers, teachers, non-governmental organizations, merchants, business associations, and the like. This will be difficult to coordinate and jump-start. The PVO/NIS Project has had the privilege to be able to in some small way, contribute to what will hopefully be a wave of change in Russia. Each of three partnerships -- PIRE/SALUS, Gundersen-Lutheran Hospital/Dubna Educational Center, and CECHE/HEF-ROZA and ADP -- has chosen a slightly different approach for their efforts. In turn, each has had admirable successes. By choosing a niche that will complement and supplement other efforts in this area, these groups are effectively working together to effect change. And they have effected change in their own way.

PIRE/Salus, has developed a unique system of training trainers to train others in a humanistic approach to alcoholism and its treatment. In the process, it has exposed a large number of Russian health professionals all across the continent to new concepts in the biological, social, psychological and physical aspects of alcoholism and its treatment and recovery, and has set up Salus-like treatment centers in two cities far from Moscow -- St. Petersburg and Chita. Salus has also become more self-confident as an NGO, and is taking the lessons it has learned through the PVO/NIS Project to begin other programs in Moscow that will greatly expand the treatment facilities for all Russians -- not just those who can afford Western style treatment. Gundersen-Lutheran Hospital, has had the opportunity to be instrumental in the development and sustainability of at least five quasi-independent alcohol treatment centers based on Western models. These centers have begun to make a dent in the problem of alcoholism in this region of Russia. By

combining a program of intense training, regular organized media events, and consistent supervision and support of trainees, this partnership has demonstrated that alcohol is a problem that can be combated, given hard work and concerted community efforts. CECHE has been instrumental in the development of a network of public health organizations joining together to influence policy makers about matters that affect the health of the Russian people. By giving their Russian partners the opportunity to decide for themselves what these issues are and what strategies to use to change public opinion and governmental policy, CECHE has provided HEF/ROZA and ADP with some unique experiences and tools. In the process, they have created a surge of activity and interest in developing anti-alcohol campaigns and legislation that will work in Russia because they were created by Russians. Together, these groups are working in far-ranging places such as Dubna, Rostov, Chita, Novosibirsk, St. Petersburg, Nizhny Tagil, and of course Moscow. They are choosing different approaches such as media campaigns, political advocacy, advocacy to narcologists and health workers, and of course new methods of treatment and recovery for alcoholics that take into account their families. Hopefully, by targeting different places and different groups to influence, the efforts of these partnerships under the PVO/NIS Project have begun to change the opinion of the public and municipal governments such that eventually Russia will no longer be known first for vodka and its consumption and second for everything else.

- <sup>1</sup> Levine, Barrett G.; Nebelkopf, Ethan; Wright, Mary Kay. "Alcoholism and Drug Abuse in Russia: Clinical and Historical Perspectives", American Journal of Addictions, 1994.
- <sup>2</sup> Ibid.
- <sup>3</sup> Ibid.
- <sup>4</sup> McCormick, Sandra, Unpublished proposal to World Learning PVO/NIS Project, 1994.
- <sup>5</sup> Ibid.
- <sup>6</sup> The National Center on Addiction and Substance Abuse at Columbia University, *The Cost of Substance Abuse to America's Health Care System: Substance Abuse and the American Woman*, 1996.
- <sup>7</sup> Bredy, Posner, Lang and Rosati, *Risk and Reality: Implications of Prenatal Exposure to Alcohol and Other Drugs*, 1994.
- <sup>8</sup> Ibid.
- <sup>9</sup> *The Sourcebook of the Criminal Justice System, 1995*
- <sup>10</sup> Penn State web site
- <sup>11</sup> op cit., Columbia University
- <sup>12</sup> Columbia University Record, March 8, 1996, Volume 21:19.
- <sup>13</sup> op cit., Columbia University
- <sup>14</sup> Ibid.
- <sup>15</sup> Morvant, Penny, "Alcohol Takes Toll on Russian Men", Omri Digest International, March 13, 1996.
- <sup>16</sup> Rutland, Peter, "Alcohol Prime in Deaths", Omri Digest International, October 25, 1996.
- <sup>17</sup> Ibid.
- <sup>18</sup> "Health of the Population", in Environmental and Health Atlas of Russia, Murray Feshback, editor, 1995.
- <sup>19</sup> Ibid.
- <sup>20</sup> Mar. M. Elaine, "The Dying in Moscow", Harvard Magazine, September-October, 1996.
- <sup>21</sup> Op cit., Feshback.
- <sup>22</sup> Wright, Mary Kay, unpublished proposal to World Learning PVO/NIS Project, 1994.
- <sup>23</sup> Ibid.

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## Central European Center for Health and the Environment

Grant Award: \$400,000.00

Actual Expended: \$400,000.00

Start Date: 19-Sep-94

End Date: 31-Dec-96

To foster the development of a network of Russian NGOs to address public health policy, service delivery, information, and communication. Each of the participating Russian NGOs is partnered with a US PVO to focus on specific health care programs such as a media campaign on alcohol abuse, food safety policies, and the integration of disabled children into their communities. In a broader context, the program establishes a Nucleus Network of Russian health care NGOs to spread information among a variety of health care NGOs via e-mail to more effectively advocate for improvements in public health.

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**Lutheran Hospital - LaCrosse****Grant Award: \$500,000.00****Actual Expended: \$500,000.00****Start Date: 25-Oct-94****End Date: 31-Mar-97**

To create the "Dubna model" for rural alcohol treatment in Dubna and three nearby towns with an emphasis on alcoholism as a health problem and the need for a continuum of anti-alcohol services. The program provides training to counselors and expands the availability of Alcoholics Anonymous, Alanon, Alateen, 12-step programs, and in-patient treatment facilities in cooperation with local government and medical institutions. The Dubna Education Center is developing two programs: school-based teenage alcohol prevention and treatment for women alcoholics.

**Partner Organizations:*****Gundersen-Lutheran, (formerly Lutheran Hospital - LaCrosse) (LHL)***

1910 South Avenue

LaCrosse, WI 54601 USA

**Tel:** 608-782-7300**Fax:** 608-791-6334; 608-791-4367**E-mail:** 71075.1173@compuserve.com**Contacts:**

Ms. Sandra McCormick, Vice President Business Development

Ms. Barbara Pretasky, Project Coordinator

***Dubna Educational Center (DEC)***

Universtetskaya, 19

Dubna, 141980 Russia

**Tel:** (096) 214-5698**Fax:** (096) 214-5698**E-mail:** huruh@univ.dubna.ru**Contacts:**

Ms. Elena Titova, Administrative Financial Coordinator

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**Pacific Institute for Research and Evaluation****Grant Award: \$710,000.00****Actual Expended: \$710,000.00****Start Date: 26-Sep-94****End Date: 31-Mar-97**

To expand alcohol treatment capabilities through training of chemical dependency professionals, a drug and alcohol abuse prevention campaign for teenagers, a media campaign, and dissemination of alcoholism statistics and information. The program brings together numerous US and Russian chemical dependency NGOs to utilize their expertise and provide each other with training, resources, and information. Alcohol addiction treatment facilities and an e-mail bulletin board are important components of this project.

**Partner Organizations:*****Pacific Institute for Research and Evaluation (PIRE)***

172 Lancaster Road

Walnut Creek, CA 94595 USA

**Tel:** 510-946-9238; 510-938-7754**Fax:** 510-946-1522**E-mail:** [salus@well.com](mailto:salus@well.com)**Contacts:**

Ms. Mary Kay Wright, Executive Director

***Salus International Health Institute (Salus IHI)***

2-a Pravda Street, Room 8

Moscow, 125124 Russia

**Tel:** (095) 971-32-87**Fax:** (095) 971-32-87**E-mail:** [salus@glas.apc.org](mailto:salus@glas.apc.org)**Contacts:**

Mr. Yuri Holkin, Coordinator of Chemical Dependency Training

Ms. Olga Petroukhina, Director

**ENABLING NGOs IN THE NEW INDEPENDENT STATES:  
---A Case Study of Disability Sector NGOs**

Margot Mininni  
The PVO/NIS Project  
June, 1997

## **Introduction**

There are 15 million disabled people in Russia. This is 10% of the population of 157 million. In Ukraine 6 million are categorized as disabled out of a population of 54 million or 11.2 %. These numbers include the vision and hearing impaired, those in wheelchairs, victims of polio,) as well as those with some birth defects, and cleft palates and some of those diagnosed with cerebral palsy. Environmental factors cause a number of deformities. Due to underreporting and an increase of disabilities due to war, (land mines), the numbers are probably greater and are increasing. Lack of wide application of genetic testing or prenatal surgery to correct defects *in utero* result in many more disabled children with correctable problems than need be. Forced delayed birthings or other delivery traumas cause a high incidence of cerebral palsy—or what is diagnosed as cerebral palsy—in the population.

Operations to correct club foot, spinal irregularities (e.g., bifida), or cleft palates are not performed in many towns and rural areas due to lack of resources or technical know-how at the local hospitals, and many children who might otherwise go on to lead normal lives, are left to sit at home or languish in institutions where many are sent by families without the knowledge or means to care for them. To those numbers are added several thousand children with learning disabilities and fetal alcohol syndrome.

Of course children are not the only victims of countries too poor to either correct their problems or treat them in such a way as to enable independent living. Adult men and women also disabled by wars, economic catastrophe, accidents at work or on the road, or illness, also are forced to drop out of a normal productive life because of a lack of prosthetic devices, wheelchairs or even crutches.

Ironically, because local and national governments have lacked the resources to rectify or treat some of these problems, and because cultural and psychological barriers have prevented them from taking anything other than a “protective” approach to disabilities, they have actually been shouldering a staggering economic burden in payment of disabilities stipends to families of disabled people as well as in institutional care. This is not to say the care is always good—sometimes children and adults are tied to beds, and fed gruel, with little therapy or stimulation. Still there is some cost. Certainly it would be better for these disabled people themselves, their families, society and the State, if they could live independent lives outside of institutions, hold jobs and otherwise lead normal lives.

## **Disability and the PVO/NIS Project**

Through awards made to US organizations with partners working in Russia, Ukraine, and Belarus, the PVO/NIS Project administered by World Learning, addressed both the correctable disabilities and those that are lifelong. Examples of programs dealing with the correctable or treatable disabilities are Operation Smile, and its local affiliates, Operation Smile Moscow and Operation Smile St. Petersburg; Christian Children’s Fund and

Belarussian Children's Fund; International Research & Exchanges Board (IREX) and the Center for Curative Pedagogics; Project Harmony and its partner the Palace for Youth and Creativity; and Elwyn Inc. and the Fund of Ukraine for the Protection of Invalids (Disabled).

Those programs which dealt with helping the disabled population help themselves, or to "mainstream" into an independent living and working situation and deal with overcoming physical and attitudinal barriers through advocacy and leadership included: The World Institute on Disability (WID) and its partner the All Russia Society for the Disabled (ARSD), (two grants); San Francisco State University Wheeled Mobility Center and its partner The Novosibirsk Regional Center for Disabilities (NRCD), (formerly the sports club FINIST) and WMC with Planned Parenthood of Northern New England and its partner the women's club Ariadne of the NRCD; Access Exchange International (AEI) and its local partner the Moscow Charity House (MCH) and the United Ukrainian American Relief Committee (UUARC) working with the Lviv United Regional Trade Union Council (LURTURC).

With a mandate to address the needs of the vulnerable and strengthen the local organizations working with them, the PVO/NIS Project not only worked with the vulnerable—the sick, and old and unemployed women and men—it went a step farther. It worked with the invisible of society in these countries, the disabled population. It is to the credit of USAID that it recognized immediately this group and from the first tranche of funds awarded, it included grants to those working with disabilities. In 1992, there were many pressing economic, health, and social problems, yet USAID always kept these most marginalized of groups in mind. In four of five solicitations, projects working with disabilities were awarded grants.

Eleven of forty-six programs (23.9%) received \$4.8 million of \$19.2 million (25%) of PVO/NIS grant funds to work in the disability sector. These grants were disbursed in amounts that ranged from \$245,000 - \$650,000 with an average award amounting to \$436,000. These relatively small amounts of money were given to organizations working not only in Russia's Moscow and St. Petersburg, but in far north Karelia, Siberia, south and west Ukraine and Belarus to accomplish small but concrete goals.

What USAID or World Learning could not then realize, was the powerful effect in many spheres and many strata that these awards would come to have, both on the disabled beneficiaries of these grants, and on the psychology and outlook of societies in these countries toward disability. Perhaps even more remarkable is that the local NGOs working in these countries, would grow to be among the best organized, most focused and capable of advocacy of any groups in the Third Sector. Perhaps prophetically, USAID's charge in an early solicitation criterion to "create an enabling environment" for the Third Sector, would come to be most clearly realized in the NIS through the environmental and disability organizations.

Of course the enabling environment USAID had in mind was the forging of a legal arena more conducive to the functioning of nongovernmental organizations that served the needs of a nascent civil society. While this is being accomplished, those groups working with disabilities also have had to contend with the entire external environment of physical barriers and psychological obstacles that keep many people virtual prisoners in their homes and needless wards of the state.

### **Raising Awareness Within and Without**

What became so important to the impact these groups would have was the immediate psychological impact small changes in people's lives began to have, first upon the disabled people themselves, then upon their doctors or caregivers and families, and then through the assertiveness of the disabled groups, upon society itself.

This seemingly intangible outcome is illustrated concretely in the results of some of the programs that made the invisible visible, and displaced ignorance with knowledge:

*"Before we started our work in the Palace of Children's Creativity, very few disabled children took part in Palace activities and no Palace teachers had the desire to work with children with disabilities. The teachers either thought they had a lack of skills or that children with disabilities cannot be integrated into activities with "regular" children. After initial attempts were made at integrating disabled children in small numbers into Palace activities, it became clear both that Palace teachers have the ability to work with disabled children and that disabled children have the ability to integrate with other children. Many parents whose children have been diagnosed as "uneducable" have come to our center looking for some sort of educational outreach which they can now receive due to the help and openness of Palace teachers."*<sup>1</sup>

*"The situation in Ukraine today is such that the disabled found themselves in an especially difficult situation, especially children. At an early age, right after being diagnosed, (sometimes incorrectly), the child is assigned the status of invalid and from that point the family starts to fight for the fate of the child, for his ability to occupy an appropriate place in the future life among normal people.....Due to the work carried on under the grant given by USAID in Mikolayev and early intervention techniques we are helping them to overcome their physical and cognitive problems. The child comes to the Center for 3-4 hours so the intensity of rehabilitation depends on how the family treats the child, how it follows the recommendations of the specialists of the Center. Through games and communication children master necessary pre-school programs and acquire appropriate behavior patterns that will enable some of them to eventually attend regular schools....a big change from the classification.... 'invalid'."*<sup>2</sup>

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<sup>1</sup> From the Final Report of Project Harmony. Susan Matson. October, 1996.

<sup>2</sup> From a monthly report to Elwyn, Inc. of Valery Lyachenko, Deputy Director, Fund of Ukraine for the Protection of Invalids. September, 1966.

*“When I viewed the film about Mr. Ed Roberts (founder of the World Institute on Disability) I was thrilled. I saw that this man who could not breathe or move without help, saw no obstacle and instead helped many. When I saw many people going to school and riding transport I saw what was possible to do with no excuses. For the first time, if I may say I feel proud to be an invalid, or at least not ashamed and see what I can do. I see that Mr. Roberts was helped by more accessible surroundings and we must begin there.....”*<sup>3</sup>

*“It is very important not to halt this process. Even the smallest gain inspires us to solve the most complex problems. People believe in themselves and believe that they can not only ease their own life but help others to believe in themselves.”*<sup>4</sup>

One really cannot overstate the profound impact that this change in outlook or psychology has had upon the “disability rights” movement in Russia and Ukraine especially. People with disabilities in these countries for many years, accepted their confinement to homes due to lack of accessibility as their unfortunate lot in life. While faced daily with apartments with no elevators or no working elevators, poorly functioning wheelchairs (or wooden platforms on wheels), and dependent upon family or acquaintances with vehicles for trips to hospitals, they did not much question this lack of accessibility and chronic pain. Those with hearing and sight impairments, while mobile, fared equally poorly in employment in anything but “sheltered workshops.”

Once American and European disabilities organizations began to find partners among the disabled societies, sports clubs and rehabilitation centers and showed their films, introduced their models, or brought them to international venues for training, and meetings, things quickly began to change. People began to see themselves as deserving of such basic rights as curb cuts, proper prostheses, or a chance to get out of their homes. So did the families, especially those with children who had long been deprived of any but the most institutional recreation.

Ironically what helped both these western and local groups to achieve their goals with alacrity and with much greater success in terms of building sustainable, ongoing organizations, is the stalwart nature forged by their disabilities. Long inured to obstacles and used to indifferent or unaware officials, they were much less daunted by such difficulties than their colleagues in other sectors. Despite the physical barriers that still exist, these groups have managed to form coalitions, come together (no small undertaking), demonstrate, write petitions and begin to effect changes in their physical and legal surroundings. And by doing so they have earned the respect (and resentment) of their non-disabled counterparts. They prevail, not in spite of the obstacles in their path, but probably because of lifelong experience in dealing with obstacles. Their coalitions

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<sup>3</sup> Comments from a participant after External Environment Training in Dneproderzhinsk, November, 1995.

<sup>4</sup> History of the Organization Ariadne, Larisa Tokareva, November 1995.

have come together and remained strong, because many of the pieces were in place prior to the beginnings of these western partnerships.

### **Building Coalitions, Developing Organizations**

With their children or relatives marginalized and ostracized these parents or mates had long since formed small groups to transport, find recreation or care for those no one else wished to acknowledge. Now with the tools and training for networking (computer information networks such as that started through the IREX grant and WID II grant) and coalition building (WID I grant) these groups have come together in a professional and sustainable way.

The paratransit system pioneered by Access Exchange International for the elderly and disabled people of Moscow built a "core system model by joining the vehicles drafted by Moscow Charity House to those of one-two and three-van systems initiated out of desperation by disability groups and their friends in Moscow."<sup>5</sup> AEI's program benefited much from volunteer drivers and dispatchers and its program also helped strengthen the volunteer model in Russia.

*"With the help of Wheeled Mobility Center we formed a women's organization called Ariadne within the framework of the disabled sports club, FINIST. The women have a difficult level of disability...and the women's organization is made up of about 60 people, but every month new women come to our organization. The first stage in building our organization was to meet and discuss problems, work out a strategy and tactics. ...women would meet after sports practice, at disabled people's talent competitions and during visits to the sauna...."*<sup>6</sup>

"After attending the Parent to Parent training sessions as well as the World Learning-sponsored Human Resource Management Conference, Vera Trebova, from the Karelian provincial city of Kondopoga created the NGO "Vera," which supports families of children with special needs. This organization now has over 50 members and has seen huge successes since its inception...."<sup>7</sup>

When people get together regularly, they begin to become an organized force with influence. This influence was manifest in many ways. Parents and disabled people themselves began to make organized requests for legislation for benefits, schools and ramps for the disabled population. These groups became visible and began to gain

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<sup>5</sup> Tom Rickert, Director of AEI, in *Initiatives*, Winter 1993-94 page 5.

<sup>6</sup> History and Goals of the Organization Ariadne by Larisa Tokareva, November, 1995

<sup>7</sup> Project Harmony, final report, September, 1996.

credibility and to be taken seriously. Local businesses or city administrators found buildings for groups to use as disability training centers. In small but important ways institutional structures that make a place for disabled groups have begun to change.

*“Teachers for local centers of Mikolayev and other cities of Ukraine were trained here and this made it possible to open centers in all districts of the city, to help centers from Dnepropetrovsk, Lugansk, Zhitomir, Lviv and the Crimea. The Ministry of Healthcare, the Ministry of Social Defense of the Population of Ukraine, the Ministry of Education of Ukraine...became interested in Early Intervention methods....in June 1996 the state enterprise Shipbuilding Yard 61 gave the building of a former pre-school to the Center so the disabled children got a building of their own.”<sup>8</sup>*

*“Several words about what has happened at FINIST during this time. We are getting ready agreements with Hospitals #6 and #27 (the latter is the one where the chief doctor is a Deputy) on providing accessibility for people in wheelchairs and on their having a priority in getting serviced. I am trying to involve other hospitals as well into the work we have been carrying out with hospital #6.”<sup>9</sup>*

*“Because of the project, a department to coordinate work with children with special needs was created in the Palace of Children’s Creativity. Irina Maslova, KDCP’s Russian full-time program coordinator, was named as head of the department and in the next quarter convinced city administrators to increase the amount of paid academic hours teachers from the Palace receive, from 20 to 75 hours per week.”<sup>10</sup>*

Institutions, attitudes and laws, however do not change by themselves and again, with the exception of environmental groups, few other interest groups have used media, public demonstrations or education as effectively to advocate for change as have disabled groups or parents of disabled children. One factor, however, that these groups have had to overcome is that, while well organized within a certain disability (there are associations for the blind, the hearing impaired and those using wheelchairs), these groups tend to work within their own associations. Only recently when regional or national laws and compensations for disabled people have been challenged, have these groups begun to come together to broaden their reach in advocacy efforts.

One of the first programs funded in 1992 under the PVO/NIS Project was one that focused on training of leaders within the disabled community, under the direction of the World Institute on Disability and its partner the All-Russia Society for the Disabled (ARSD). With almost twenty thousand affiliated groups and 1.3 million disabled people across Russian under seventy-eight boards divided regionally, the ARSD’s ties helped

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<sup>8</sup> Valery Lyachenko , Monthly report to Elwyn from the training center. September, 1996.

<sup>9</sup> Excerpt from a Letter from Victor Semenko, chairperson of Finist Executive Committee to Marc Krizack, project Director for Wheeled Mobility Center. April 1997

<sup>10</sup> Final Report of the Karelian Disabled Children’s Program of Project Harmony. Susan Matson.

WID's trainers and facilitators reach a broadly dispersed population. Early in the project, after initial meetings and trainings, WID was able to identify a strong group of emerging leaders within the disabled community as candidates for further training, some of them as trainers themselves.

Also identified for greater focus in training were three major areas: organizational management; development of information and communication skills and work with the media; and development of disabled-owned businesses for sustainability. In addition to basic accessibility, integrating disabled people into society, and women and disability, were the issues the leaders decided were most important.

Regionally WID found that Ufa, in Bashkortostan (near the Ural Mountains), Moscow and Southern Russia were strongly responsive to project training. They also did some work in Novosibirsk. It is important to mention here that since three World Learning subgrantees with disability projects were based in the San Francisco Bay area there could be a lot of overlap and sharing of resources both in Russia and in the training of Russian NGOs in the U.S. This supplied reinforcement of training of all three groups and broader perspectives on more than one issue pertaining to disability (e.g. wheelchair design and mobility from Wheeled Mobility Center; leadership and business development from WID and paratransit systems as well as accessible local transportation issues from AEI). In Russia the Moscow and Novosibirsk regions especially benefited from the World Learning umbrella as well as the geographical proximity of three groups with expertise in disability issues in the same U.S. location.

If Ed Robert's trip to Moscow in April 1993 was a defining moment for the physically disabled in Russia, so too was the wheel-chair dance troupe performance in August of that year, also in Moscow. Bruce Curtis was among the ensemble of disabled and non-disabled dancers which had a powerful psychological impact upon the Moscow audience of disabled and non-disabled alike. This performance and a similar one in Novosibirsk by the Axis Dance Troupe twenty months later, seemed to empower the local disabled community with the belief that anything was possible. This in turn fueled an active movement of public education and advocacy for accessibility and health disability rights.

## **Advocacy**

Already in April of 1993, the working groups formed under the first Russian-American seminar held by WID and ARSD drafted a declaration to President Yeltsin which they submitted in May, with forty-five signatures. This declaration called for a new law on disabled people's rights and social protection, guarantee of services, fair representation by disabled people on the President's Coordinating Committee on Disability, special tax status for disabled-owned enterprises and it called for integration of disabled people into all aspects of civic and social life.<sup>11</sup>

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<sup>11</sup> Declaration on the Problems of Disabled People in Russia, Moscow, April 29, 1993.

This was the beginning of a process of consciousness raising by ARSD and WID of the local governments and national legislators as well as society. In December 1993 President Yeltsin signed a decree recognizing disabled citizens annually on a special day. In addition Alexander Lomakin was asked by the Duma committees on disability to act as an advisor on the drafting of disability legislation. This law addressed inaccessibility of buildings and public transportation and the limitations of laws already on the books. Finally in January, 1995 the *Law On Social Protection of Disabled Persons in the Russian Federation* was passed by the Duma. This embraced a set of federal medical programs such as *Medical and Social Expert Study and Rehabilitation of the Disabled, Research Backup and Information Framework for Disability; Creating an Environment Accessible to the Disabled; and Design and Manufacture of Artificial Limbs and Construction, Modernization and Technical Updating of Orthopedic Enterprises.*

The Federation law was vetoed by Yeltsin in February 1995 and went back to the Duma committees for reworking. ARSD officers, especially Tamara Zolotseva worked on changes to the law, but also set about to educate the lawmakers on where compromises could and could not be made through letter writing campaigns, service on advisory committees and reports and coverage in the media. She and others also realized that in addition to a need to have a basic federal law on the books, it was very important to work on regional and city laws on disability rights.

Also, WID's project personnel, especially Bruce Curtis found it important to emphasize the necessity to ARSD to work on two levels at once: getting basic legislation on the books, and then having a strategy and process for implementation. This was particularly difficult in the NIS where there was no tradition of Rule of Law to uphold legal challenges to governmental agencies by citizens or litigation for enforcement.

This spawned yet another grant to WID, this time under the auspices of IREX in 1995, to work with ARSD staff on learning provisions of the law and developing strategies for implementation. They brought in lawyers from the US who had been key litigants in implementation of the Americans with Disabilities Acts as well as ARSD and legal specialists in Russia well-versed in all aspects of the legislation to train Russian leaders in Moscow and in the regions.

One of the regions where legal consultations on the law and basic litigation take place with some regularity is Novosibirsk. The legal company "Konsul" under the Direction of Yulia L'vutina, has a steady stream of disabled clients requesting information, support or legal redress from the lawyers of Konsul. In one three month period Konsul reported:

- 42 people seeking information on the rights and benefits of people with disabilities;
- 10 people seeking reimbursement for damage to health
- 7 seeking information about housing rights
- 16 seeking information on labor, family, criminal, civil code issues.

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An additional fifty persons called for legal consultations and another fifteen visited the office and these included parents and relatives of people with disabilities, those seeking damages as to health and arbitration court processes.<sup>12</sup>

In August, 1996 several women from Ariadne staged a demonstration in the metro system of Novosibirsk to draw attention to the need for accessible transport. With the assistance of volunteers and soldiers, they had themselves carried down into the stations and onto the platforms and trains where they passed out pamphlets, made speeches and endeavored to educate the local riders about their plight.

*"We were carried into the stations and disrupted some of the day's commute. Some people ignored us, others were angry and annoyed at us, some cursed at us, but many were interested and some were sympathetic and said they had never before understood our situation."*<sup>13</sup>

*"Yulia is starting a court process against the city and regional administrations because the benefits for people with disabilities are included into the law but have not yet been implemented. This is our first attempt to fight with the city officials for our rights using a legal basis."*<sup>14</sup>

Yulia L'vutina of Konsul and the women of Ariadne have succeeded in getting the attention of the local transport and municipal government in Novosibirsk who are responding to the demonstration and legal inquiries through a task force promising to look into accessibility.

*"The transformation of FINIST from a disabled sports club into a service and advocacy organization was central to our organizational development efforts...FINIST's primary efforts are not aimed towards "help(ing) the handicapped learn to do sports that they never dreamed they could do before." Instead, it seeks to improve wheelchair accessible transportation, remove architectural barriers, and advocate on behalf of the rights and interests of people with disabilities in Novosibirsk. Those other goals include equality, civil rights, and the integration of people with disabilities in all areas of economic and social life. These are precisely the goals of FINIST and of our AID-sponsored partnership."*<sup>15</sup>

While basic legislation on disability also exists in Ukraine, implementation remains a problem. Disability groups there, however have advised on the legislation and have organized for advocacy and fund raising. Halyna Tazaracheva, Director of the Fund for the Protection of Invalids (Disabled) was a member of the drafting committee for the national law on disability of Ukraine and active in outreach.

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<sup>12</sup> Yulia E. L'vutina, writing in Konsul, quarterly report to Wheeled Mobility Center, July 1996.

<sup>13</sup> Letter to Margot Mininni, of the PVO/NIS Project from Larisa Tokareva, of Ariadne, May 27, 1997.

<sup>14</sup> Letter from Viktor Semenko(Finist) to Marc Krizack of Wheeled Mobility Center, April 3, 1997.

<sup>15</sup> Letter from Marc Krizack to Gregory Brock of USAID. February, 1997.

*The Mikolayev department of the Fund for the Protection of Invalids was one of the initiators and main organizers of the Center and its work. It raised money from and educated civil, private groups and individuals and received work from architects, designers and builders for free or at cost.*<sup>16</sup>

Peter Podpruzhnikov, an officer of the Kharkiv NGO Association and director of a local Parents of Disabled Children's organization has begun to organize Ukraine's many disability groups in the twenty-four regional jurisdictions of the country into a nationwide network. In June 1996, he succeeded in convening a conference of a variety of disability organizations in six of the twenty-four regions who began discussing a national agenda of disability concerns and a charter for such a national network.<sup>17</sup>

Access Exchange International (AEI) and its primary partner, Moscow Charity House stands as a precursor to and an excellent example of a community development program. With a primary goal to provide paratransit to the infirm elderly and disabled population of Moscow, the project harnessed the volunteers provided by Moscow Charity House, together with the specialists in transit in California and England who in turn worked closely with local city officials including MOSGORTRANS (Moscow City Transportation Authority) bus park #7. Not only did this project provide close to 50,000 (one way) para transit trips per year (door to door), but was instrumental in getting a pilot program started in a selected part of Moscow that outfitted city buses with special lifts, and built ramps at selected bus stops along with curb cuts. (Moscow bus route # 803).

Again, because of the World Learning umbrella and previous collaboration within the Bay area of the USPVOs, AEI was able to extend its reach beyond Moscow and to reinforce the work of WID and WMC. With advocacy on disability rights issues and the independent living movement as cornerstones of their respective projects, accessible transportation, public and private, becomes an important building block. Tom Rickert, the Executive Director of AEI and one of his project's primary consultants on accessible municipal transportation systems, James McLeary have both visited Novosibirsk and St. Petersburg to discuss with local authorities and NGOs, ways and means of accessible transport. Thus as one local NGO advocates for legislative changes and another publicly demonstrates for change, a third organization provides local officials with expertise and a place to turn to begin to answer demands. Some of these local officials have visited the United States, Finland and England and are aware of European and American models in practice. In addition leaders of ARSD and staff of Wheeled Mobility Center and AEI's Valeria Sviatkina have attended international conferences and fora discussing accessible transport and disability issues in Europe, the United States and Australia.

This work and these consultations continue on well past the life of the grant. Valeria Sviatkina continues to maintain contacts not only with Moscow Charity House but with MOSGORTRANS, and officials of St. Petersburg. As recently as June 1997, she was actively participating in local transportation conferences in Moscow along with visiting US consultants.

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<sup>16</sup> Valeriy S. Report to Elwyn, Inc. from Fund for the Protection of Invalids., Sept. 1996.

<sup>17</sup> June 1996 Quarterly report of GJARN and July 1996 interview with Margot Mininni during a World Learning monitoring trip.

## **Sustainability Through Economic Development**

Early on in its first project in Russia, the World Institute on Disability identified development of enterprises under the All Russia Society for the Disabled's umbrella as a priority for achieving self-sustainability. ARSD controls about 1350 enterprises employing about forty thousand people, of which about nineteen thousand (50%) are disabled. These enterprises range from production and repair of clothes, production of footwear and repair of televisions and watches; transport, wallpapering, construction, plaster work, and sports installations. Fewer than half (45%) of the businesses even used a computer. Business incomes averaged \$700,000 per annum with the highest income \$6 million and the lowest \$6. Some enterprises employed as many as 570 workers and some as few as 5 people (average was 134 employees). About 2.2% of business is foreign.<sup>18</sup> Major foreign trading partners included England, Denmark, Germany and the United States along with Ukraine, Belarus, Kazakstan and Latvia.

In a later solicitation, WID was successful in getting a second project funded under World Learning's umbrella that focused on fulfilling the goal of developing and strengthening ARSD's enterprises through management training and the development of a network of internal trainers and business consultants. The "Organizational Strengthening of the ARSD through Sustainable Economic Development Project" devised a model training program based on regionally implemented courses in business plan development, management training with some marketing, media outreach and communication network development. Training took place in regions such as Perm, Rostov, Sochi, Volgograd and Nizhny Novgorod. In all, eleven regions participated. Electronic mail networks and telecommunications equipment and training were provided. Selected trainees were designated for further training as business consultants/trainers. With fifty-seven business directors from eleven regions beginning the training, thirty-one completed all cycles.<sup>19</sup>

After the initial successful training the ARSD's Central Board awarded \$100,000 in funding to enterprises in a competition seeking good business proposals for future development. The ARSD considered this an investment in its own sustainability since fifty per cent of its operating budget comes from these businesses. This technical assistance program, however, also enhances the organizational capacity of the local organizations and businesses and is an example of a local Russian organization actively donating its resources to NGO and business development.

In Novosibirsk, the first project of San Francisco State University, Wheeled Mobility Center (WMC), set out to provide the region with portable, lightweight and heavy duty wheelchairs based on a design pioneered by Ralf Hotchkiss of WMC and develop a competitive production/distribution system as well. These chairs were to be produced locally through a system of managed competition among local enterprises as well as have

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<sup>18</sup> Robert Metts, Nansea Metts & Tracy Dodson Echeverria, Final Report on the Business Plan Training Component of the Organizational Strengthening of the ARSD Through Sustainable Development Project, January, 1997.

<sup>19</sup> Bruce Curtis, Seventh Quarterly Report for the Organizational Strengthening of the ARSD through Sustainable Economic Development Project, August 1996.

their design tested locally and augmented by local engineers. One of the participating production facilities SibMed Design (SMD) developed a good working relationship with WMC and FINIST. This is a mutually beneficial arrangement which has promise of fostering sustainability.

*We have worked with SMD very well. They will start to produce wheelchair lifts which help to put a wheel chair on top of a car. The auto repair workshop is run well and it develops. We rented more space there. Specialists from the auto repair workshop fix and repair wheelchairs as well as cars. We have been negotiating with Anna Stepanovna Petukhova in order to get her consent for the following: we would like the Social Protection Ministry to place orders to our auto repair shop for pre-sale preparation (check-up) of cars with hand controls, which will then be distributed among people of the city and region with disabilities.*<sup>20</sup>

In western Ukraine, in the economically depressed Lviv oblast, the vocational training program for needy and disabled children expanded to include nine towns and schools. Administered by World Learning subgrantees the United Ukrainian American Relief Committee (UUARC) and Lviv United Regional Trade Union Council (LURTURC) trained over four hundred students in woodshop/carpentry; sewing; and merchandising and salesmanship through the running of small thrift shops in each region.

Approximately eleven program graduates have been placed in steady employment. What is important to realize here is that these students would have not received any training otherwise, and can now take care of themselves rather than relying on the State. They also have found work at a time when large parts of the population are suffering chronic under employment or unemployment due to the economic situation. In addition approximately another 80 students (many with learning or other disabilities) (22%) have gone on to take university or other schooling due to the confidence built by acquiring tangible, valuable skills.<sup>21</sup>

### **Summary**

Thus, by looking at several of the disability programs funded by USAID through World Learning, it is possible to also see a profile of the NGO sector itself and a successful model of organization, outreach and sustainability. These programs were extremely successful for a variety of reasons:

- the NIS partner and US PVOs were appropriate and very well-suited to fulfilling project goals.
- the disability groups were already organized into service or support-type groups (parents of disabled children, regional sports clubs, associations of the blind...etc.), although sometimes these categories proved too confining, and some effort had to be assigned to broaden the scope of these groups' networks. In general however, this made organizing into larger networks and advocacy groups much more natural.

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<sup>20</sup> Letter from Viktor Semenko, FINIST to Marc Krizack, April 2, 1997.

<sup>21</sup> UUARC: Final Report, December 1996 and follow-up phone conversation with Christiya Senyk, June 10, 1997.

- members of these groups were already marginalized and accustomed to indifference and barriers—this made them—and the US PVOs working with them—more able to persevere and remain undaunted in the face of obstacles and inevitable delays.
- the psychological impact of small successes and self-awareness translated into a powerful force which was channeled in a variety of ways among disabled groups: enthusiasm to reach out to media, new resolve to demand rights, a new interest in meeting others like themselves and a concomitant demand for transportation and accessible buildings.

Each project by itself was small, yet dollar for dollar, each made an impact upon disabled individuals, local groups, local authorities and legislation well beyond what its funding would have predicted. This impact was profound and positively affected the disability sector, reached well beyond the region where it was implemented and by extension became a real force that motivated, informed and arguably even defined, the NGO sector itself.