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**The Novosibirsk Disabled Community Health Clinic:  
A Cooperative Program by Medical Professionals  
and Disabled Consumers**

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Report submitted to World Learning and USAID

June 15, 1997

# FINAL PROJECT REPORT

## Novosibirsk Disabled Community Health Clinic: A Cooperative Program by Medical Professionals and Disabled Consumers

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Grantee Name: Wheeled Mobility Center at SFSUF

Grant No: NIS-2022-00-46

Name of NIS Partner(s): Novosibirsk Regional Center for Independent Living "FINIST"

Country sites: Novosibirsk, Russia

Grant Amount: \$450,000

Grant Start/End Dates: 11-07-94 to 12-31-96

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Date of Report: 6-15-97

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## Executive Summary

### Project Objective and Goals

The long term objective of the project was the integration of people with disabilities in Novosibirsk, Russia into all aspects of social life. The project began with four principal goals. The first was to establish a Disabled Community Health Clinic within a larger medical facility in Novosibirsk, Russia, with an advisory board composed of people with disabilities. The second was to train Russian medical professionals to recognize and treat the special medical needs of people with disabilities. The third was to train disabled Russians to provide on-going training through peer support programs to other disabled Russians and their families in the prevention and treatment of the secondary effects of disability, such as pressure sores and bowel and bladder problems, as well as reproductive health issues such as menstruation, menopause, pregnancy, childbirth, contraception and abortion. The fourth principal goal was to develop the leadership capabilities of disabled women in ARIADNA, women's sector of the Novosibirsk Regional Center for Independent Living FINIST (Phoenix).

### Project Results

#### *Disabled Community Health Clinic (DCHC)*

- Established a wheelchair accessible health clinic for people with disabilities in Polyclinic #6 located on the left bank of the Ob River. The clinic began operating in November 1995 and is open three days per week. One hundred and ninety-seven people with disabilities received complete physical examinations and, where necessary, medical treatment.
- Reached agreement in principle with the director of Polyclinic #27 to establish a second DCHC in this more modern and centrally located facility. This second clinic opened in May 1997.
- Established Disability Resource Center at Library for the Blind as main repository for all disability-related materials, health and otherwise.
- Established satellite resource center at Polyclinic #6.

#### *Training of Medical Professionals/Health Care Providers*

- Conducted three trainings for medical professionals at Polyclinic #6, medical professionals from NIITO, the trauma hospital, and other health facilities, and for city officials. Trained 3 NIITO employees, 3 doctors from Polyclinic #6, 4 doctors from the Children's Rehabilitation Center, 2 doctors from the regional hospital, and 2 ambulance doctors, 2 doctors from the Russian Family Planning Association.

### *Peer Education*

- Held 3 formal trainings and trained 26 people with disabilities of whom 23 are women, in peer education training techniques. More than half of the trainees participated in more than one training.
- Peer educators conducted at least four small-scale seminars for other disability groups. Peer educators provided individual counseling to peers in the DCHC, the Trauma Institute (NIITO), as well as in people's homes.

### *Organizational and Leadership Development*

- Held 1 formal leadership training seminar for ARIADNA members with emphasis on team leadership, strategic planning, and public education through the media.
- Supported FINIST sponsorship of citywide Disabilities Festival.
- Helped increase the membership of ARIADNA, the women's sector of FINIST, from three active members and five occasional members to 12 active members and 40+ members overall.
- Assisted/supported ARIADNA with fund raising efforts (benefit concert).

### *Translated into Russian or Provided Existing Russian Language Materials*

- Living with MS, Debra Frankel, National MS Society (1993)
- Cerebral Palsy - Facts and Figures, United Cerebral Palsy Association
- Yes You Can! - A Guide to Self-care for Persons with SCI, Paralyzed Veterans of America, 1989
- Bladder Dysfunction, Multiple Sclerosis Society
- Genital Infections and Sexually Transmitted Disease, Magee Hospital
- Planning Your Family, Magee
- Menopause, Magee
- Your are becoming a woman, Magee
- Self-Breast Exam Cards, Magee
- Nine Months of Pregnancy, Magee
- Spinal Network -
  - Spasticity Control
  - Bowel Management
  - Skin Care: You Can't Take the Pressure
  - Aging and Disability
  - Autonomic Dysreflexia: Know what To Do
  - Sex for Men
  - Sex for Women

#### Birth Control

- "Rehabilitation Medicine - Principles and Practice," Lippencott  
Ch. 35 Pressure Ulcers  
Ch. 36 Neurogenic Bladder Dysfunction
- "The New Our Bodies Ourselves"
- "Disabled Village Children," David Werner
- Breast Cancer Handbook, Cassileth and Foote, 1995
- Contraceptive Technology - Bridging the Gap
- Guide to Reproductive Health Care (JHPIEGO)
- How to Plan Your Family (a flipchart)
- Guide to Breast Cancer
- Standard Guidelines and Rights for People with Disabilities (UN)

#### *Employed or Provided Employment in Novosibirsk for:*

- One (1) full time doctor/project coordinator, one (1) full time Peer Education Coordinator, and three (3) part time positions as transportation dispatcher, clinic intake and outreach workers. All of these jobs were performed by ARIADNA members.
- One part time treating physician and one part time nurse at Polyclinic #6.
- One full time Russian-English interpreter/translator for duration of project.
- One half-time accountant for duration of project
- Four regular part time positions within FINIST/ARIADNA
- Numerous temporary positions primarily for drivers, translators, and interpreters.

### **BACKGROUND TO THE PROJECT**

The Disabled Community Health Clinic (DCHC) project, which began November 7, 1994, was conceived as a complementary addition to WMC's existing World Learning/USAID funded project in Novosibirsk. The earlier project had begun in June 1993 and would end December 31, 1995. It had as its main goals the development of wheelchair production and the transformation of our partner, FINIST, from a disabled sports club into an independent living center (ILC). An ILC is a non-residential service and advocacy center run by and for people with disabilities.

A key component of WMC's strategy for turning FINIST into an independent living center was mobilizing disabled women and developing their leadership abilities. We had realized during the first six months of 1993 that the existing organizations of people with disabilities in Novosibirsk were extremely bureaucratized. We also recognized that the women members of each of these organizations were by and large excluded from leadership positions. We felt that women of all disabilities could come together in a powerful grassroots movement which would reverberate throughout all of the existing organizations. We believed that ARIADNA could provide the opportunity for disabled women activists to develop their

leadership abilities so they could take their rightful places as leaders of the entire disabled community and could be a force for uniting people with differing disabilities at the grassroots level.

A second key component of our strategy for transforming FINIST into an ILC was giving FINIST the opportunity to become a service provider to the disabled community. We viewed service provision not only as an end in itself but also as a means to building a stronger disabled community which could effectively advocate in its own interest. FINIST, and its women's sector, ARIADNA, could develop its membership base and organizational clout by reaching out to the disabled community through service provision. In the process of providing services FINIST and ARIADNA activists could also gain valuable practical management and leadership experience.

A program to develop non-governmental organizations of people with disabilities in Novosibirsk required a strong health care component. Many disabled people have special medical needs which can be easily and inexpensively managed, but which if not properly managed can lead to serious illness, infection and even death. Yet the professional medical community in Novosibirsk was woefully lacking in its understanding of those special medical needs, as was the case in the United States 25 years ago. This lack of understanding had an especially onerous impact on disabled women who also have to contend with a variety of reproductive health problems. All manner of medical problems went undiagnosed and untreated, leaving disabled women at risk for disease and unintended pregnancy. Accurate, quality sexuality education was not available and the little available information was outdated and inaccurate. Even worse, there were numerous cases of medical professionals pressuring pregnant disabled women into having an abortion.

FINIST members had made it clear that one of the most pressing needs was health care appropriate to the special medical needs of people with disabilities. When we began the DCHC project we expected that the clinic would be almost exclusively concerned with these special problems which are secondary medical effects of disability. Yet we had not foreseen how little access people with disabilities had to general primary health care. Everyday life in Novosibirsk was especially hard for people with mobility impairments because few buildings in Novosibirsk, and not one hospital or polyclinic, was wheelchair accessible in 1994. The same was true for the city infrastructure as a whole: lack of curb cuts, ramps, no accessible public transportation, narrow doorways and passages, high steps, barriers at the doorway, etc. As a consequence, many people with mobility impairments were forced to stay at home and had no possibility to visit a health care facility. As a result, we would spend more money for general medical exams than we had originally intended.

## **HISTORY OF THE PROJECT**

The DCHC project started about sixteen months after WMC had begun to work with what was then the Novosibirsk Regional Disabled Sports Club FINIST. The organization was in the throes of a struggle between the original, entrenched leadership and a group of

wheelchair rider activists who wanted the organization to address their needs. (For a blow-by-blow account of this struggle see the final project report "Wheelchair Building in Novosibirsk, Russia: A Comprehensive Program of Economic and Social Development," June 1, 1996). WMC had been encouraging wheelchair riders to become involved, and we had also made special efforts to organize disabled women. These efforts began to bear their first fruits in October 1994 when what had up to then been known as the Disabled Women's Program formalized itself as ARIADNA, with by-laws and elected officers. The development of ARIADNA as a quasi-autonomous part of FINIST would bring hitherto inactive disabled women into organizational life. But at the same time, ARIADNA's ambiguous status as part of FINIST yet not part of FINIST would sow confusion and further discord. This was the whirlwind in which the DCHC project was born.

### *Initial Strategy*

The first eight months of the project were divided between the search for the right medical facility in which to locate the DCHC, and our first training of the future peer educators. Three factors converged to slow progress toward selecting an appropriate site for the clinic. They were 1) Reluctance on the part of the Novosibirsk medical community to become involved in rehabilitation medicine, an area they knew little about and which carried no prestige; 2) continuing internal struggles within Finist; and 3) the need for an ongoing dialogue with FINIST members themselves who needed time to assimilate modern concepts of rehabilitation.

At the end of our initial assessment visit in February 1995, WMC made a major adjustment in plans by deciding to bifurcate the project and move ahead with the resource and education aspects of the project separate from the treatment aspects. There were two primary reasons for this shift. First, the medical establishment was not showing much interest in serving people with disabilities, nor in low tech and low cost alternatives for prevention and care. Second, Yuri Lesnevsky, director of the Special Library for the Blind, was eager to collaborate with WMC & FINIST. Lesnevsky had grown comfortable with the idea after meeting and befriending WMC's then on-site project coordinator, Elizabeth Schuster, who is herself vision impaired. The Special Library has a program for delivering talking books (tape recordings) to blind persons, and Lesnevsky recognized that people with mobility impairments could benefit from a similar program.

Rather than wait until we found a suitable location for the clinic, we decided to separate the clinical functions from the resource and educational functions. We did this both because we did not want to lose valuable time and because we wanted to take advantage of Lesnevsky's willingness to cooperate in order to build a cross-disability movement. Lesnevsky's interest in having vision and mobility impaired individuals and their organizations cooperate was unusual in the Novosibirsk disabled community. There, as throughout the world, disabled people have historically been divided along disability lines, with separate organizations for blind people, for deaf people, and for people with physical-motor disabilities. These organizational divisions had created separate communities based around a particular

disability. Additionally, as products of the Soviet period, the older established organizations in Novosibirsk were extremely bureaucratized. The effect was to magnify the natural tendency to organizational isolation among differing disability groups, promoting competition instead of collaboration and significantly weakening the disabled community's ability to gain its fair share of the public resources. We knew that cooperation with Lesnevsky would be a major step forward, the first significant cross-disability cooperation in Novosibirsk.

The plan was one thing, getting it approved by FINIST with its contentious factions was another. We planned to present this proposal, in detail, to the interested FINIST activists. The day before the planned meeting in mid-February 1995, we learned that original FINIST members Sergei Malakhof and Grigorii Vasiliev were telling people that the FINIST council had "sold out to the Americans." Victor Semenko, who has since been elected and reelected chairperson of the FINIST Council (executive committee), said that Malakhof and Vasiliev just wanted WMC to give them the money and let them do what they wanted. What they wanted was hocus pocus massage and herbal treatments. We were assured that few others shared their opinion.

Six men and six women attended the health project meeting. All the women and Victor Semenko were named to the Health Project working group. Malakoff did not show. We were told that he said he wanted \$10,000 up front or he would not have anything to do with it. It is not clear why Grigorii Vasiliev did not show. Semenko said they knew they had lost, so why bother showing up. The FINIST membership approved the plan, which called for a Disability Resource Center to be housed in the Library for the Blind.

The ARIADNA Disabled Women's Program lead the way in making the agreement with the Library. This initial cooperation led a few months later to an agreement between the Library and ARIADNA which began holding its monthly meetings at the Library because the FINIST office was too small for large meetings.

In June 1995 the formal agreement was signed between FINIST and the Library whereby the resource and education portion of the project would be located at the Library. The agreement included a twice monthly home delivery service in order to bring health resource materials and a planned FINIST newsletter to those persons unable to get to the library. It would prove helpful in keeping the disabled community informed during the long, cold winter months, although FINIST was not able to take full advantage of this service because it produced only one issue of its newsletter during the grant period. Social Protection, represented by Anna Stepanovna Petukhova, also signed and agreed to pay \$1000 to make the Library wheelchair accessible. Lesnevsky knew from the beginning that \$1000 would not be enough to do the job. But by getting Anna Stepanovna to agree to pay \$1000, he had involved her in the project. The actual amount transferred by Social Protection in July 1995 was \$1444, the total cost of the remodeling job.

## *The Disabled Community Health Clinic*

In February, 1995 Dr. Lyubov Popova volunteered to work with FINIST to find an appropriate site for the clinic. Dr. Popova, herself disabled as a child from polio, is a pediatric surgeon with 20 years experience. FINIST had found her through their needs assessment survey the previous November. Without Popova's enthusiasm, expertise and city-wide connections, the clinic may never have gotten established. Popova's efforts to find an acceptable location for the clinic continued through June. Many head doctors were quick to agree to most anything we wanted as long as they could get our money. Some locations were too inconvenient, others lacked even the basic equipment. One institution looked like it might go bankrupt. With our eyes focused on sustainability, we were careful not to rush into an arrangement which would only collapse at the project's conclusion.

In early May, after many failed meetings, Dr. Popova met Dr. Vitali Melnikov of Polyclinic #6. Located on the left bank of the Ob River, this clinic and hospital were 90% owned by a metal working factory that had been recently privatized. Under the Soviet system the clinic had served the workers of this factory and been paid by the state. Now, the factory had to pay the clinic and because business was slow, the factory was unable to pay in cash for treatment its workers received there. Consequently, the factory was paying the clinic by constructing a new building for the polyclinic's use. This barter arrangement had the benefit of allowing the polyclinic to avoid taxes, but it meant that the clinic still needed cash to pay salaries and purchase equipment.

Dr. Melnikov offered FINIST a 15 square meter room on the first floor for various types of treatment. In lieu of rent, he offered the use of the room and of all other hospital facilities, for up to 200 disabled people, in exchange for the cost of equipping the room and providing money to pay for first exams. (These are not covered in the government insurance program, but follow-up and treatment are.) The 200 complete exams, at a cost of about \$75 each, would provide the polyclinic with a significant cash inflow. Sustainability was addressed by a clause in the agreement that service would be offered for five years or else the equipment purchased with AID funds would be returned to FINIST or purchased from FINIST at the then current market value. WMC Project Managing Director Marc Krizack's insistence on including AID requirements on equipment purchase almost torpedoed the agreement as Melnikov angrily exclaimed, "American aid is not for humanitarian purposes but just to sell American equipment, even if it isn't the best equipment available." Only after superb diplomatic efforts by Victor Semenko (who coincidentally had been treated as a child by Dr. Melnikov in his home village) and Lyubov Popova, and a heartfelt appeal from Krizack were things smoothed over so that a good agreement was finally signed. The agreement would also provide the polyclinic with \$40,000 in durable medical supplies and modest salaries for one doctor and one nurse.

This offer seemed sound to many FINIST members. What clinched the deal was the possibility that the first floor of the new building then under construction would be made into a rehabilitation center. At the end of June an agreement was signed. The clinic was

supposed to go into operation in September. But Summer vacations, Popova's attendance at the UN Women's Conference in Beijing, and late delivery of some equipment from Saint Petersburg delayed the opening until November, 1995. Dr. Popova's successful efforts earned her the position of Health Project Coordinator.

By the project's close in December 1996, the DCHC was operating three days per week (Monday, Wednesday, Friday) from 2:00-5:00 p.m. The DCHC consists of one examination room to which the different specialists come to examine the clients. The examination room is wheelchair accessible, but it is too narrow. The height of its height adjustable gynecological chair cannot be adjusted because the handle is jammed up against the wall. By the project's close, 197 people had received a complete physical exam. The clinic saw an average of 15 people per month for specific treatment. A complete physical exam involves an examination by a general physician, ophthalmologist, ENT specialist, urologist, neurologist, and gynecologist. In addition, urine and blood tests are taken from all clients and if indicated an EKG, X-ray of the lungs or ultra-sound of the stomach area is performed.

Lack of sufficient regular transportation was the biggest factor in limiting the number of patients seen at the clinic. Frequent breakdowns of the FINIST bus meant that those who need to use a wheelchair to get around had fewer opportunities to visit the clinic.

### *Peer Education and Training Teams*

Planned Parenthood of Northern New England (PPNNE), a subcontractor of WMC under this grant, brought the Peer Education and Training Team (PET) concept to the project. The PET teams were integral to our efforts to develop disabled women's leadership skills and to make quality health information available to people with disabilities in Novosibirsk. In May 1995, PPNNE gave the first of three seminars. This was the first formal activity since WMC began to work with FINIST in 1993 that was aimed toward disabled women, and it provided the first concrete opportunity to organize and mobilize disabled women. Larisa Tokaryeva, ARIADNA president, had intentionally invited women from each of the city's nine districts in order to reach out into the disabled community. Judy Cyprian and Katherine McLaughlin of PPNNE gave a detailed week-long seminar on sexuality and peer education for fifteen women, some of whom were new to the ARIADNA women's group. The seminar was especially effective because one of the two PPNNE trainers was a wheelchair rider herself, which helped establish immediate rapport and credibility with the participants. Cyprian and McLaughlin also conducted a one-morning men's workshop on the same theme.

Soon after the workshop, two of the ARIADNA women who had participated in the training conducted their own formal seminar. Two women also went to NIITO, the trauma hospital, to speak with newly disabled persons. Many of the other women held informal talks with those of both sexes on the themes discussed. The participants' enthusiasm for the seminar, however, was tempered by their lack of confidence to go out on their own and form PET teams. It would take additional trainings and organizational support from WMC and PPNNE before significant progress could be made.

Between the first and second PET seminars, the women became involved in a number of activities under WMC's concurrent World Learning grant. These activities, although not directly health related, helped foster managerial and leadership skills and build self confidence.

In the Spring of 1995, ARIADNA members wrote a successful grant proposal to the Global Fund for Women. Dr. Lyubov Popova attended the UN Beijing Women's Conference. Two teenage girls, Natasha 16 and Zhenya 17, attended a Mobility International USA training in Eugene, Oregon in Fall 1995. This training was highlighted in the PBS series "People in Motion" which first aired in April 1996. ARIADNA raised part of the travel costs themselves through the business community. In early June 1995 8 FINIST members, 4 of them women, attended an independent living training in Helsinki. In late June 1995 AXIS Dance Troupe, an Oakland, California-based integrated group of disabled and non-disabled dancers, gave performance workshops in Novosibirsk with funding from the National Endowment for the Arts. ARIADNA members actively organized the visit.

ARIADNA also began to function better when Svetlana Lyapunova, who was ARIADNA's first vice-president, left to set up her own organization serving the general NGO community. Although as a former municipal deputy Svetlana was well connected, she had also been a source of tension within ARIADNA.

During this period FINIST's leadership began to change as well. A new "working group" of wheelchair riders, which included two women, won 6 of 7 seats on the executive committee. The coalescing of this new leadership group and the prospect of many upcoming activities created an atmosphere of hope and enthusiasm.

By the end of September 1995, the project had 1) Created a working alliance with the Library for the Blind, the first such cross-disability alliance in Novosibirsk. 2) Established a site for the medical clinic. 3) Arranged for the purchase of durable medical supplies for the clinic 4) Conducted a medical information survey 5) identified qualified personnel to run the program, and 6) Provided the most important English language materials in rehabilitation medicine and reproductive health for translation into Russian.

Despite these activities, the second PET seminar revealed the women's continuing lack of confidence and need for stronger organization and leadership. The task of training or presenting to medical professionals was a daunting one. Client-centered care, meaning the provision of care based on what the client expresses as her/his needs, was difficult for the medical providers to grasp. It would take time and frequent contacts with FINIST/ARIADNA members before the traditional medical professionals with whom FINIST worked could accept that people with disabilities can play a role in decisions about their own health care.

PPNNE held a second 3-day PET seminar and a 4-day seminar aimed at training health care providers in October 1995. PET member participation as presenters in the providers training

drove home the importance of client-centered care and laid the groundwork for the participation of disabled women in operating the Disabled Community Health Clinic. Also, by holding these seminars at the Novosibirsk affiliate of the Russian Family Planning Association, the project helped establish connections between the disabled community and the reproductive health care community in Novosibirsk.

When the clinic began operating in November 1995, the project paid the salaries of FINIST/ARIADNA members to run the clinic's outreach, scheduling, and intake functions. Dr. Lyubov Popova, a pediatric surgeon who is herself disabled from a childhood bout with polio, managed the project for FINIST. This arrangement provided disabled women with an opportunity for practical managerial experience while firmly establishing FINIST in a formal advisory relationship with the treating practitioners. Whereas WMC's initial push for the establishment of an advisory committee had been rebuffed by polyclinic #6 and then abandoned by FINIST as a necessary compromise to get the DCHC up and running, the hiring of disabled women to perform practical functions resulted in the creation of a defacto advisory committee.

In April 1996, ARIADNA would augment this group by hiring Lyubov Ivanova, a disabled woman, to coordinate the peer education efforts, thus providing more direction and structure in this area. Ivanova organized monthly meetings for the peer educators, identified areas for further training, and organized peer education opportunities. She also provided counseling and information materials to clients of the DCHC.

Working closely with Irena Bosker, WMC's on-site coordinator, Ivanova and Dr. Popova developed a questionnaire to assess the needs of clinic users and to evaluate the clinic's effectiveness. The results of the August 1996 survey show that a large majority of the clients rated the services of the clinic as "excellent" (26%) or "good" (62%). Further, the survey also showed the important role FINIST played for the clients to receive such health care: 85% of the clients came to the clinic on invitation of FINIST and 68% got to the clinic by the FINIST bus. The clinic survey also evaluated the performance of the FINIST peer educators at the clinic. All the clients who met a peer educator at the time of their visit, thought her presence and counseling was helpful. The same holds true for the health education and information materials seen by the clients: only one respondent (3%) thought the materials were disturbing; others thought they were helpful and informative. The results of the survey demonstrate and emphasize the importance and need for such health care services for people with disabilities.

The success of PPNNE and WMC's efforts was revealed in September, 1996 when nine women from ARIADNA attended a women's conference in Novosibirsk organized by World Learning. The conference was entitled "Women: Better, Stronger, Wiser for a Healthier Tomorrow" and was attended by more than fifty women from different non-governmental organizations from all over Russia. On the last conference day six of the ARIADNA women took part in a presentation on the topic of advocacy. They spoke specifically about all the different ways in which they advocate for themselves, including their peer education work,

their work in the clinic and trauma center, their work with the government to increase curb cuts in Novosibirsk for wheelchair riders, and their recent Metro demonstration (see below). For many of the women it was the first time they had spoken before such an audience, which in itself was an empowering experience. The positive response of the other attendees made them realize how much they had accomplished.

### ***Training of Medical Professionals***

Although we had originally planned to provide training to medical professionals at the outset of the project, lack of a clinic site and lack of interest by the medical professionals caused us to delay these trainings. Working with people with disabilities was not very prestigious work in Novosibirsk. The term and the content of rehabilitation were not very well understood, nor was significant rehabilitation provided to people with disabilities, not even to those with recent traumatic injuries.

The first trainings of medical professionals occurred through the October 1995 PPNNE seminars and dealt primarily with disabled women's health issues. From June 24 to June 29, 1996 there was a training in Novosibirsk for medical professionals conducted by Dr. Robert Haining, head of Pediatric Rehabilitation at Oakland (California) Children's Hospital and Jo Ann Duprat, RN, head rehabilitation nurse at Oakland Children's. The main theme was the secondary medical effects of disability. In conjunction with this training we had several chapters of the textbook: Rehabilitation Medicine, Principles and Practice (J.B. Lippincott Company) translated into Russian. Haining and Duprat also visited a number of orthotics and prosthetics workshops and identified one, run by Ivan Sasnukh in Berdsk (just outside Novosibirsk), as a good candidate for future support. Funding permitting, we would like to bring Sasnukh to Oakland for 2-4 weeks to work with some local orthotics and prosthetics makers. Sasnukh has a more open and creative view of orthotics and prosthetics design, although he is also interested in helping wheelchair riders walk, which interest we feel is misplaced. He has support from the Regional Department of Social Protection through Anna Stepanovna, who recently gave Sasnukh \$5000 for his work. Sasnukh is aligned with the All Russia Society of the Disabled (ARSD), although he operates independently and thus has more room to maneuver.

### ***Development of ARIADNA, Disabled Women's Sector of NCIL FINIST***

From its inception ARIADNA has been viewed, by members and non-members alike, primarily as a social and cultural organization, and the level of political consciousness has remained fairly low. Yet paradoxically, ARIADNA members have been among the leaders in FINIST's efforts to reach out to the disabled community. During the "ride the metro day" demonstration, it was the ARIADNA women who took the lead and furnished the overwhelming majority of participants. This was due in part to the fact that those already holding down leadership positions within FINIST were hesitant to jeopardize their relationship with government officials and so did not want to "rock the boat." The more militant political activism of ARIADNA women, at least during the metro demonstration,

must also be attributed precisely to ARIADNA's social and cultural character. ARIADNA provides frequent opportunities for disabled women to get together for dance, choral, and sports activities. These activities are always well-attended (provided there is sufficient transportation), and they have been instrumental in bringing disabled women out of their isolation and creating a sense of loyalty and community. Although it may be hard to justify US government funding for purely cultural activities by overseas NGO's, ARIADNA is an excellent example of how cultural activities, taking place in the overall context of NGO development, can be the glue which holds an organization together.

## **OTHER ACTIVITIES**

### *Seating & Pressure Sore Seminars*

Customized seating specialists Jamie Noon, formerly of Stanford Children's Hospital, and Jean Anne Zollars, author of a custom seating manual published by Otto Bock Company, gave two seminars in Novosibirsk in October 1995. The first, held for nine working days in the First of May District Disabled Children's Center, dealt with postural support seating for children of different ages and disabilities. Four children attended regularly, as did SibMedDesign (SMD) engineers and several massage and design specialists from other health care centers. Some people, including doctors and parents, attended from time to time and were useful in spreading information about the seminar to others who were interested. The seating seminar provided the opportunity to concretely link FINIST with the active Parents of Disabled Children (PDC) organization in the First of May District. In the Spring of 1996 this collaborative effort bore further fruit when the PDC signed an agreement to collaborate in FINIST's computer training program. The computer training project was funded through a grant from the Eurasia Foundation through US-Russia Connect, Novosibirsk's sister city organization in Minneapolis, Minnesota.

The second Zollars-Noon seminar was a three-day workshop on pressure sores and their prevention through the use of locally-available materials for adult seating cushions. The Zollars-authored manual was translated into Russian, and six adult custom cushions were successfully completed.

### *Disabilities Festival*

A Disabilities Festival entitled "The Concept of Independent Living" took place from August 28-30, 1996 in the Dom Offitsirov (Officers' House) in the center of Novosibirsk. The festival was entirely organized by FINIST, with minimal assistance from WMC in the conceptual stage, and consisted of seminars, presentations, videos, and exhibits on a wide variety of topics all centering on the theme of independent living, including independent living in the US and other countries, medical aspects of disability, legal advocacy, sports and rehabilitation, architectural barrier removal and barrier free design, and accessible transportation. An average of 90 people attended each day of the 3-day festival, and several representatives from the city and oblast administrations, the transportation department, the

metro services, and from different rehabilitation centers attended parts of the festival as well. Further, as part of the festival, FINIST organized a public demonstration - with TV coverage - which included a ride on the metro by 20 people with disabilities, most of whom are women and 10 of whom are wheelchair riders who were assisted by uniformed soldiers. The purpose of this demonstration was to raise awareness among the general public about the inaccessibility of the city's public transportation system and to insist on the right to equal access. Because the ride on the metro was not an officially sanctioned demonstration, FINIST members did not want to carry signs. They also did not want to give out leaflets in the metro because they did not want to be associated with the Mormons and Hare Krishnas who do the same. Although the demonstration was not very militant by American standards, it galvanized the participants for further action. This was a big first step for them, and one of which they could feel justly proud.

### *Medical Supplies*

On September 10, 1996, a 20-ft container with medical supplies and equipment arrived in Novosibirsk and was held in Russian Customs until June 1997. It seemed that there was no end to requests for additional, duplicate, and/or irrelevant documentation, such as letters stating that FINIST is the owner of the container's contents and an invoice showing the cost of shipping (which is based on volume, not cost of transported goods). When one issue is resolved, another crops up. Customs' final obstacle was a claim that additional paperwork needed to be done because the contents of the container were used, even though 90% of the container's items were new. Some medications had expired by the time the container was released. The pressure relief cushions, catheters, and other rehabilitation supplies and equipment, including a dental chair, were still good, but obviously did no good locked away in a warehouse for nine months.

### **SUSTAINABILITY**

Thoughts of the future led FINIST to draft a written agreement between NCIL FINIST and the Center for Independent Living in Berkeley, California to formalize a sister CIL relationship based on an October 1996 oral agreement between FINIST Deputy Chairperson Stas Pachgin and CIL Executive Director Michael Donnelly.

In December 1996 FINIST and WMC reaffirmed their on-going partnership agreement. In fulfillment of that agreement, Alexander Afonin of the SibMedDesign wheelchair factory is presently doing a one-month internship at the University of Pittsburgh Human Bioengineering Research Laboratory where he is studying wheelchair testing.

In the Spring of 1997 ARIADNA held a benefit concert to raise money, expand their fund raising skills beyond grant writing, and build community support.

In May 1997 a second disabled community health clinic opened up at polyclinic #27. Although Dr. Popova talks of having both clinics open, the lack of funds for transportation

will mean that only one or the other will be fully functional. Dr. Popova says that had she known about polyclinic #27 back in early 1995, she would have set up the DCHC there. Most likely both clinics will function at the beginning because it would be politically too difficult to abandon polyclinic #6. Then, more and more of the functions will be transferred to polyclinic #27. Now that the container has been released from Customs, the dental chair and most of the other supplies will be located at polyclinic #27. In the end, polyclinic #6 will continue to provide services only to people on that side of the river who are able to get to the clinic on their own.

Polyclinic #27 is a far better place for the DCHC. It is much larger, much cleaner, and much brighter than Polyclinic #6. It is only a few minutes car ride from FINIST, and close to the Gagarin metro station. Its director is a woman who also sits on the Novosibirsk City Council, a significant asset in a country where everything seems to turn on political connections. Unfortunately, the Novosibirsk city council is made up of 19 Liberal Democrats (Zhirinovskiy), 11 Communists, and only 7 "true" democrats. This alignment means great difficulties for FINIST in getting government financial support for the DCHC although funding has often been promised.

Dr. Popova would very much like to see the DCHC function as a rehabilitation polyclinic instead of merely providing physical examinations and general health care for people with disabilities (PWD). If she is successful in gaining the political support to make this happen, continuity of the DCHC will be assured.

With the project ending, FINIST will have to cut back on the transportation it provides. Whereas up to now anyone who wanted to go to the clinic could arrange for transportation through FINIST, now only FINIST members will be able to get transportation on demand. FINIST will provide its bus two times per month for non-members. And although full medical exams will no longer be provided without some special source of funding, regular medical insurance will cover specific treatments required.

In November 1996 FINIST received a one-year grant from the Soros Foundation to conduct two Peer Education Training sessions per month through the end of 1997. FINIST also received a grant from the Kingdom of The Netherlands Fund to put out 12 issues of DIALOGUE, FINIST's newsletter, through Spring 1998.

Irena Bosker has been diligently pursuing contacts within the European Community and has found a Dutch NGO to partner with FINIST in a proposal to TACIS which would be a continuation of this grant with a bit more emphasis on rehabilitation.

Dr. Popova will be speaking at the international women and disability forum in Washington, DC in mid-June 1997 and is expected to follow that with a brief visit to Oakland Children's Hospital. Two women from ARIADNA are expected to attend an MIUSA leadership training in Oregon this Spring and then attend the DC forum in June.

## REPLICABILITY

The DCHC project provides a model for establishing client-centered health care in the former Soviet Union and in developing countries. Funds for equipment, medical supplies, even doctors' and nurses' salaries were paid directly by our partner. By funding our partner, who then funded clinic operations, we were able to place our partner in a position of active influence within the clinic.

A collateral benefit of the project was the inclusion of disabled women's sexuality issues in Planned Parenthood of Northern New England's international program for the first time.<sup>1</sup> PPNNE's intention to have a disabled women's component in all its international work is an immensely positive development for disabled women and should lead to similar projects in developing countries.

## CONCLUSION

FINIST now appears to be a stable, functioning NGO. Its women's sector, ARIADNA, now has a core leadership group with experience, skills, and self-confidence. The clinic has been functioning for more than a year now with significant input from its disabled clientele. Rehabilitation medicine is gaining in prestige, at least among the practitioners who work with our program. The linkup with Hospital #27 with its director's better political connections is a very positive and hopeful sign for the future. We can say with confidence that a Disabled Community Health Clinic will continue to operate in Novosibirsk for years to come.

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<sup>1</sup>PPNNE's international program is separate from International Planned Parenthood

## ACKNOWLEDGEMENTS

The Wheeled Mobility Center could not have implemented this project without the support and collaboration of the following individuals and organizations:

Shelley Bergum, Deaf and Disabled Telecommunications Program

Edna Brean, RN

Dr. Catherine Britell

Center for Independent Living (CIL), Berkeley, California

Bruce Curtis, World Institute on Disability

Ellen Dorsch, Planned Parenthood of Northern New England

Barbara Duncan, Rehabilitation International

Ethel Dunn, Highgate Road Social Research Station

Jo Ann Duprat, RN, Oakland Children's Hospital

Arlene Essex, San Francisco State University Foundation

Bill Fisher

Sonja Franeta

Global Fund for Women

GRANDMAR, INC.

Ray Griffin, EZMT Valve Company

Dr. Robert Haining, Oakland Children's Hospital

Susan Hartman, US-Russia Connect

Tom Hetzel, Jay Cushions

International AID

Megan Kirschbaum, Through The Looking Glass

Enrique Madrinan, Bay Area Outreach and Recreation Program (BORP)

MAP International

Kathy Martinez, World Institute on Disability

Pam Mendelsohn, World Institute on Disability

Mobility International USA (MIUSA)

Jamie Noon

Maria Oginsky, World Institute on Disability

Open Society Institute

Jen Petersen, Planned Parenthood of Northern New England

Peter Pfaelzer, Wheeled Mobility Center

Brenda Primo, Director, California State Department of Rehabilitation

Suzanne Reier, World Institute on Disability

Tom Rickert, Access Exchange International

Elizabeth Schuster

Judith Smith and AXIS Dance Troupe

Marilyn M. Sorokin, MPRI-NIS

Paul Trudeau, Stanford Children's Rehabilitation Center

Winrock International

World Learning, Inc

Jean Ann Zollars, PT

# НЕЗАВИСИМАЯ ЖИЗНЬ

## *Независимая Жизнь*

*- это равные права и равные возможности*

*- это право делать свой выбор*

## Принципы независимой жизни

Люди с нарушением физического здоровья должны знать свои права и уметь их отстаивать.

Люди с нарушением физического здоровья должны иметь право самим принимать решения в своей жизни, приведет ли их это к успеху или к неудаче.

Люди с нарушением физического здоровья должны быть интегрированы в общество настолько полно, насколько это вообще возможно.

Люди с нарушением физического здоровья лучше знают, как помочь людям с такими же или подобными нарушениями, будь это конкретные услуги или эмоциональная поддержка.

Люди с нарушением физического здоровья могут добиться независимости только в том случае, если они сами активно участвуют в этом процессе.

НАША ЦЕЛЬ - это формирование такой среды обитания, где люди, как здоровые, так и имеющие физические, ограничения, будут жить в тесном взаимодействии, без отчуждения и вынужденной изоляции, будут вместе работать и вместе проводить свободное время.



"СЧАСТЬЕ" - это состояние души,  
но для этого нам не нужно ничего...

СЧАСТЬЕ - это состояние души,  
но для этого нам не нужно ничего...

# Что НАМ нужно, чтобы быть независимым

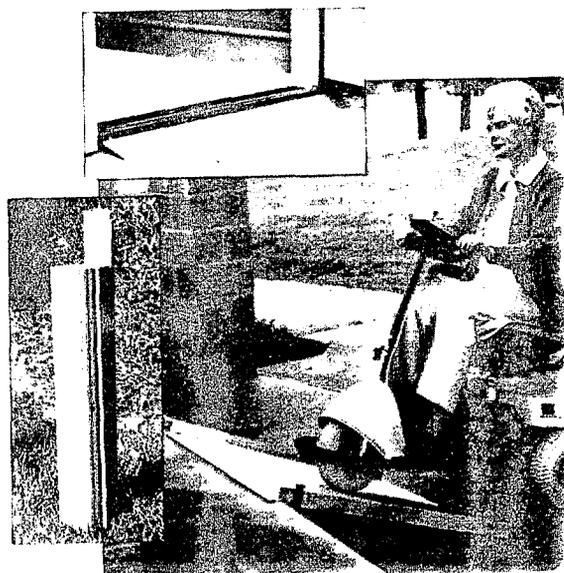
*Это:*

общественные здания,  
квартиры, улицы - должны  
быть доступными для  
людей с различными  
видами нарушения  
физического здоровья



*Это:*

- пандусы на бордюрах
- широкие дверные проемы
- отсутствие порогов
- пандусы при входах в здания



Во многих случаях обязательны

таблицы с надписями шрифтом Брайля

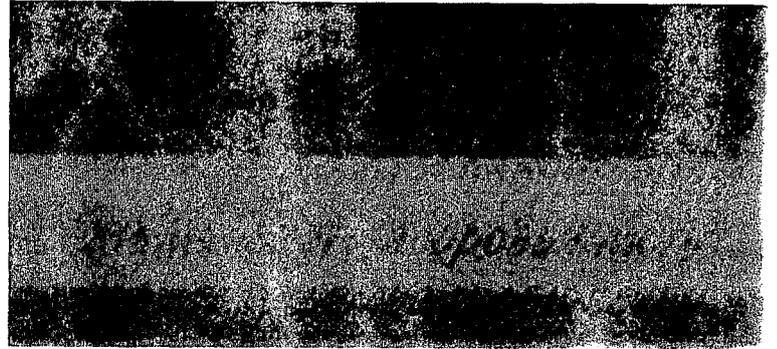
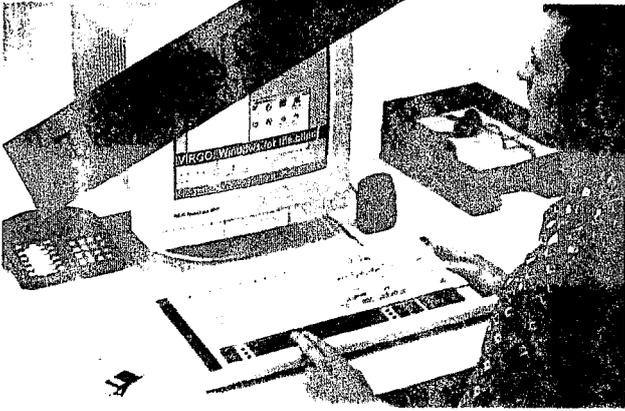
общественный транспорт  
должен быть оборудован  
специальными приспособлениями

чтобы им могли  
пользоваться люди с  
различными видами  
нарушения физического  
здоровья.

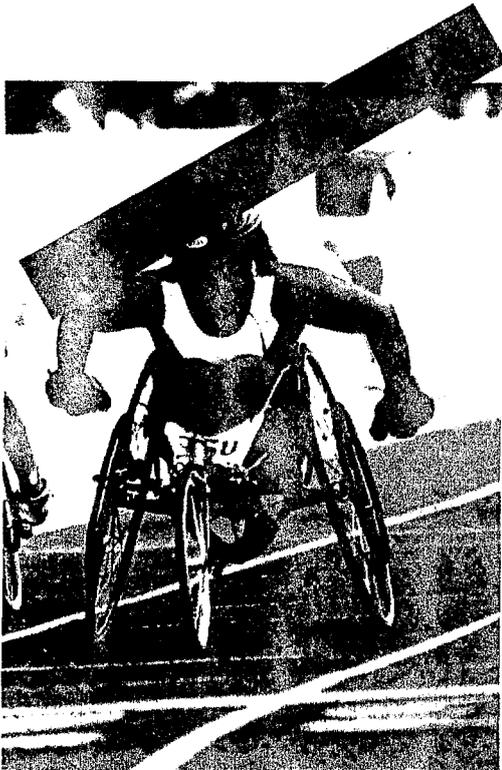


**Это:**

возможность реализовать  
наше право на труд



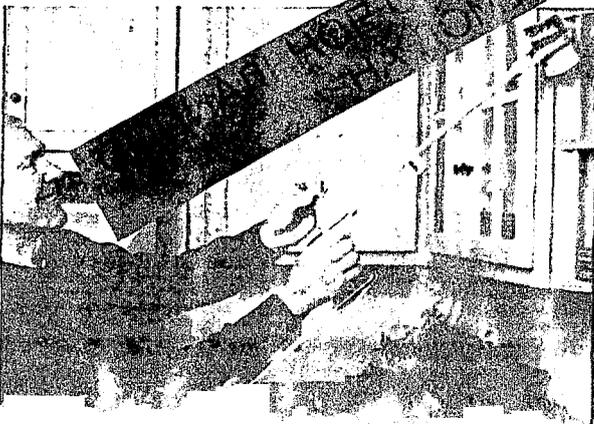
Задача должна состоять в том  
чтобы выбор направления  
деятельности человека с нарушением физического здоровья  
строился на его уникальных возможностях, качествах и опыте



"Каждый человек  
имеет право  
принимать полное  
участие в культурной  
жизни общества,  
радоваться искусству  
и получать свою долю от научного прогресса и его  
пользы"



(Декларация Прав Человека, ст.27.1)





# Центр независимой жизни

является тем местом, где люди с нарушением физического здоровья будут чувствовать себя свободными и способными создать что-либо и быть таким, какими они хотят быть

**НАШИ ПРОГРАММЫ:**



✓ Спорт и развитие творчества.

✓ Взаимоконсультирование.

✓ Медицинская программа.

✓ Юридическое обслуживание

✓ Женская программа.

✓ Компьютерное обучение с последующим трудоустройством.

✓ Производство инвалидных колясок и ремонт реабилитационного оборудования.

**БРОСЬ ВЫЗОВ СЕБЕ И ИЗМЕНИ МИР** <sup>22</sup>