“The Holocaust is a touchstone in my life,” artist Susan Erony once explained, “a place to which I cannot avoid returning because there is no understanding it and I am not capable of abandoning the quest.” Erony’s work has been shown throughout the United States and Europe with exhibits focusing on genocide and the Holocaust. In her work as a scholar and a teacher, the Holocaust has been an ongoing theme. Also, in her work as a therapist, she has been concerned with art and the healing process.

In a unique collaboration, Erony joined with Dr. Ziva Stern, Coordinator of the Jewish Family & Children’s Service program *Legacies: Programs for Children and Grandchildren of Holocaust Survivors* and offered a lecture and slide presentation to explore art and the Holocaust, and also presented a separate workshop that used art as a way of engaging in the healing process.

So many of us have asked the question, “What have we learned from the Holocaust?” It is a question as relevant as it is baffling — for our society and for each of us as individuals. But what if a survivor of such atrocities is your own mother? Your own father? Your own grandparent? For Susan Erony, the global discussion, debates, and denial are brought home daily to the most human scale, because her own father was a survivor of the pogroms in the Ukraine at the turn of the century. Many in his family were killed, and he was imprisoned.

To cope with the devastation of learning what her father had suffered, and what it had done to him, Susan Erony turned to art and research, which she says helped her to heal. “Because the Holocaust is such a gross violation of human rights, it has left me incapable of just painting a landscape,” says Erony.

For Dr. Ziva Stern, the Holocaust also has a human face that she sees every day. A child of Holocaust survivors herself and a clinical psychologist, Stern serves as coordinator of *Legacies: Programs for Children and Grandchildren of Holocaust Survivors*, founded in 1999 and funded by the Dorot Foundation.
Dear Friends:

We are well into the New Year already, and quite excited about the challenges that are ahead of us in the coming year. In this issue we look at the way Jewish Family & Children's Service reaches out to "special needs" populations. Many readers may think of a special needs population as children with learning disabilities or physical challenges. You will be surprised to find that we have a much broader view than that.

We also are not limiting ourselves to the work we do here in Massachusetts, but will introduce you to one of our successful international endeavors. We think what you will find most interesting is the scope of the programming we strive to provide, and the range of ages we serve. We have covered everything from working with children in the Ukraine, to helping parents in Massachusetts to using art to help older adults who are survivors of the Holocaust.

As always JF&CS continues to evolve and develop programs and services based on the ever-changing needs of our community. We hope you will find this edition of JF&CS News interesting. Please stay in touch and up-to-date with us by visiting our web site at jfcsboston.org.

Sincerely,
Stephen D. Lebovitz
President

Seymour J. Friedland, Ph.D.
Executive Director

The Special Needs Initiative: Helping Across the Globe

"JF&CS has always worked on behalf of children and families… our dedication remains the same whether it is in Greater Boston, Israel or the former Soviet Union."

Seymour J. Friedland, Ph.D. 
Executive Director

Parents of children with mental or physical disabilities face many difficult questions: How do I care for my child's unique needs? Where do I send my child to school? How do I secure the best possible physical care? How do I guarantee my child will have every opportunity to become a member of the community? These questions can be daunting, even for parents in the best of economic and social circumstances. But for parents living in economically and socially challenged communities such as the former Soviet Union, they can be simply overwhelming.

Life for Ukrainian children with disabilities is grim. By law, many are not allowed to attend public school. Others capable of attending school do so without the necessary benefit of special educational services. And often the problems of the post-communist economy are felt hardest by families with special needs, as the availability of adaptive and rehabilitation equipment, trained educational, medical, social service and rehabilitation personnel is severely limited.

The Dnepropetrovsk Kehillah Project Special Needs Initiative began in 1995 as a response to the unmet needs of these children and their families living in Dnepropetrovsk, Ukraine. Focusing on enhancing community inclusion and improving the quality of life, The Special Needs Initiative currently supports 35 children with a variety of physical and mental disabilities and their families, providing a continuum of caring support, including parent and staff training, vital community connections, and, most importantly, an educational resource center.

Under the continued leadership of Dr. Judith Wolf and her daughter, Susan Wolf-Fordham, Esquire, The Special Needs Initiative began with the simple realization that children with disabilities in places like the former Soviet Union did not have access to the most basic adaptive tools, much less the resources capable of making them feel more a part of their community. "We were packing my mother's bag for a trip to Ukraine," program co-chair Wolf-Fordham recalled, "when it dawned on us that children with disabilities there probably did not have access to things as basic as adaptive silverware and spill-proof cups. So my mother and I began to collect these kinds of adaptive materials for children in Dnepropetrovsk."

Within a short time, The Special Needs Initiative found a permanent home at Jewish Family & Children's Service. "When you think of helping children and families, you think immediately of JF&CS," Wolf-Fordham explained. "[Executive Director] Seymour Friedland was very supportive of our project and felt strongly that The Special Needs Initiative would be more successful if it had an agency base.

"Working with JF&CS has made an incredible difference," Dr. Judith Wolf added. "Although we had already established a strong foundation of dedicated volunteers in the Jewish community, utilizing the resources available through JF&CS and Dr. Friedland, we..."
became networked with the professional community as well. JF&CS also provided the administrative support and international expertise we needed to help our program grow. Together we have made a profound influence on the lives of these children and families.

“The Special Needs Initiative corresponds to the agency’s mission working on behalf of children and families,” said Dr. Friedland, a psychologist with clinical experience working with children with disabilities. “Our dedication remains the same whether it is our community in Greater Boston, Israel or Ukraine.”

Over the last few years, The Special Needs Initiative has worked to expand the efforts of Bet Hana Pedagogical Institute, a Jewish women’s teachers training college in Dnepropetrovsk. With financial support from Combined Jewish Philanthropies’ Women’s Division, the Jewish Community Relations Council, CIBC World Markets’ Hand-in-Hand Program and other generous contributors, The Special Needs Initiative has focused on the development of training programs for local parents and professionals in Dnepropetrovsk, as well as increasing community awareness of special needs issues among teachers and teachers-in-training there.

“The goal of the Special Needs Initiative has always been to provide an inclusive educational model,” explained Ellen Shapiro, project coordinator. For many children, involvement with the Bet Hana Education Resource Center has been their only social experience outside of the home. “Our volunteers work very hard with staff from Bet Hana to include these children and families into the surrounding community.

With help from The Special Needs Initiative and its dedicated team of volunteers, the Education Resource Center located at Bet Hana is currently moving toward becoming a full school day program for children who would otherwise be ineligible for public school, expanding its after school programs by increasing the number of sessions offered and the number of children it can accommodate, and seeking accreditation as a recognized higher degree-granting program.

“It has been amazing to watch this program grow,” Dr. Friedland added. “Within six years the program has grown from just an idea to help children in Ukraine to a substantial resource not only for children and their families but also for students seeking to be trained in the most contemporary methods.”

For more information please call Ellen Shapiro, project coordinator, at 617-558-1278.
First there is the initial shock of finding out the diagnosis. This is by far the hardest. But for the parent of a child with a severe neurological disorder (Down’s syndrome, multiple birth defects and other conditions), it is only the beginning.

There are countless medical concerns, including visits to doctors and hospitals, surgeries, medications, apparatus for breathing and feeding, wheelchairs. Additionally, the children need constant, vigilant care around the clock, which does not lessen, as the child gets older.

Add to this the fact that the general public does not understand neurological issues, the hesitancy of friends and family, and the overwhelming financial and educational challenges; and many parents find that they are facing a lonely battle.

When she gave birth to twins with cerebral palsy, Lucia Bastianelli found herself in this situation. She and her husband John didn’t know where to begin. Through her children’s school, they heard about the JF&CS Family Circle program in Norwood, part of the JF&CS Early Intervention program.

Family Circle, which began in 1999, currently serves about 80 families. The entire focus of the program is on the needs of the parents. Currently, there are very few Early Intervention programs anywhere that have this focus.

Through Family Circle, parents are encouraged to participate in Parenting Journey workshops so parents can meet each other, learn relaxation techniques, and discuss their successes, frustrations, and possible future improvements with people who are facing the same parenting challenges.

Family Circle is committed to providing any resources that are needed, through direct financial support, education and information, workshops, and networks with other families in the community. “As far as age, background, and income group, they cover every gamut possible,” says Family Circle coordinator Patty Reardon. “Childhood disability treats everybody equally.”

Formerly, Reardon was a junior high school mathematics teacher. When her second child, Patrick, was diagnosed with Down’s syndrome, Reardon became involved in the Early Intervention field, served as a parent liaison, and then began to lead parent
groups. She holds a B.S. in elementary education, a M.Ed. in counseling, and is a state certified developmental psychologist. Reardon’s son, Patrick, is now 14; her daughter, Kimberly, is 16.

Having first-hand knowledge of the challenges, Reardon stresses the need for these parents to form networks with each other.

“When you find out – when your child is diagnosed with a severe disorder – and you immediately look to the future of all the things the child CAN'T do, this can be overwhelming,” says Reardon. “We have found the best thing we can offer is the ability to talk to other parents in the same situation, people who have been in the same shoes. Just to know that ten years down the road, you can still be a normal, functioning family, is a great relief.”

Reardon says it is difficult not having the freedoms that other parents have as the child grows. For a child without severe neurological disorders, when she reaches the age of two, for example, parents can leave the child with a babysitter. But for a child with a neurological disorder, it’s not that easy. Parents are frightened even to leave the child with a grandparent or other family member. And if finding a babysitter for a healthy child is difficult, it is even harder to find someone to take care of a child with a neurological disorder.

Then, there is the sad but undeniable fact that these parents do not have the encouragement and support that other parents would have. They get the stares of passersby at shopping malls, or people walking by and pretending not to see a child in a wheelchair, with breathing tubes and other apparatus.

Add to this the financial burden, and it can be a challenge many parents find impossible.

To answer these challenges, which range so widely from the emotional to the practical, Reardon remains flexible, looking for new opportunities and ways that Family Circle can provide support.

One example is “Evenings Away,” an event Family Circle organizes once or twice a year. “For couples, so often, Mom is out the door, and then Dad is out the door,” says Reardon. “When do they get a chance to be together?”

The program pays for a babysitter, and purchases tickets for a social event for a couple to enjoy time with each other. “I was amazed to find out some of these couples had not gone out on a date in two years,” says Reardon.

To help families network with each other, Family Circle has started a Parent Directory (entirely voluntary), which lists parents, town they live in, child’s age, and diagnosis of child.

Family Circle’s monthly newsletter, sent to families, has received “lots of good feedback,” says Reardon. “Families find it very reassuring that there will be a constant source of current information.” Reardon, together with a group of parents, published a directory of area recreational activities with a $1,000 award from the Hauselin Fund. The Early Intervention Multimedia Library”, made possible by a grant from the Klarman Foundation, includes books, videos, and magazines on parenting, as well as a web site directory developed by Joanne Keady of the Early Intervention staff. Reardon works closely with Early Intervention director Donna Frodyma.

In September of 1991, Dr. Alan Pinshaw’s daughter became ill with viral meningitis.

In April of 1992, after four months at Children’s Hospital, Boston, and another four months at Franciscan Children’s Hospital, she was transferred to New England Pediatric Care. She arrived on a Thursday.

“Early Saturday morning, I went to see her, and she was dressed in a fancy new pair of woolen pajamas which I didn’t recognize.”

Pinshaw asked the nursing staff, “Where did she get these pajamas?”

They said, “Maria brought them for her.”

“Who is Maria?”

“She is the cleaning lady.”

“Why on earth would she buy my daughter a brand new pair of pajamas?”

The reason was heartbreaking. For children with severe neurological impairments, such as his daughter’s, the expectation is that “there is no family, there is no money, and there will be little support.”

“I said to myself, ‘Wake up, Pinshaw!’ If Maria could do it, so could I.”

This was the beginning of the H.A.L.O. Foundation (“Help A Little One”), and Alan Pinshaw’s service as Founder and Director. H.A.L.O. is a non-denominational foundation. “We support all comers, and our services are free of charge,” says
Pinshaw. H.A.L.O. is committed to ensuring the quality of life for children with neurological impairments. At its core are fifteen officers, directors, and advisors. Gayle Pinshaw, Alan’s wife, is also closely involved.

Founded in 1993, the initial objective of H.A.L.O. was to enhance the emotional well being of the children by taking care of their “creature comforts.” The foundation worked with pediatric nursing homes, and gave them teddy bears, televisions, and VCRs. The H.A.L.O. Reports newsletter, which began publishing in 1994, is filled with supportive words for caregivers, families, and donors, individual stories, and photos of children enjoying activities such as horseback riding, dog petting, and water therapy. The H.A.L.O. Foundation still gives away teddy bears and TVs during holiday times.

But, as Gayle Pinshaw says, “The whole enterprise has grown far beyond my wildest imagination.”

It was JF&CS Executive Director Sy Friedland’s proposal about three years ago, that the H.A.L.O. Foundation provide support not only for the children, but also for the families of those children that has brought the H.A.L.O. Foundation to the next step, says Pinshaw.

“It became our purpose to support parents with children who have severe neurological disorders, and to provide a forum for them to discuss their needs, their wants, their frustrations, their successes.” At that point, Patty Reardon, Family Circle Program Coordinator, was hired to create Family Circle.

Pinshaw has been “100% supportive,” says Reardon. “He is our biggest fan. As I have developed the program, he has given me freedom to explore new avenues, to meet parents’ needs as the program evolves, and to not get locked into a specific goal if another opportunity arises.”

The H.A.L.O. Board of Directors has also been involved with Family Circle. “They were 100% supportive,” says Reardon. “They really gave me the trust to move on with the program in a way that most benefits the families,” says Reardon.

Pinshaw’s future plans for the H.A.L.O. Foundation and Family Circle include geographic growth throughout New England and beyond, as well as new initiatives in the program itself. “I want to use what Patty Reardon has created as a model to create other circles to support more families. For example, ‘baby circles’ could be formed for graduates of neonatal intensive care units who have now gone home.”

Born in South Africa, Pinshaw left that country in 1975, and lived in London until 1977, when he moved to the Boston area. He is on the medical staff of Beth Israel Deaconess Medical Center, specializing in obstetrics and gynecology. He also holds a teaching appointment with Harvard Medical School.

As a philanthropist, his aim is “to support the small guy, the person or people or cause that is unlikely to receive support on a broad base.” Although the H.A.L.O. Foundation is non-denominational, Jewish causes are especially important to Pinshaw. “With 12 million Jews out of 7 or 8 billion people, it is incumbent on American Jews to support Jewish causes.”

As an individual, Pinshaw’s philosophy is simple.

“Help others. And reinvent yourself often.”

“Of course if a family has a specific question, they can always call me. We are always glad to help with the myriad of medical and governmental information, bureaucracy, paperwork and questions.”

With all of the evolving services, Reardon’s hands-on, personal approach prevails throughout. This has earned many “thank you” letters as well as a reputation that has gone beyond Massachusetts. Family Circle focuses its support on families in Eastern Massachusetts, although there are “a few people” who are in surrounding states who stay in touch because there is no similar service in their area.

Closely tied to JF&CS Early Intervention, Family Circle collaborates with other JF&CS programs as well. Peggy Kaufman, Director of the Center for Early Relationship Support, holds workshops for group leaders, which Reardon used to train her own facilitators. The Dnepropetrovsk Kehillah Special Needs Initiative is based in the Ukraine, and focuses on children with disabilities and their families. When their staff visited JF&CS in Boston, Reardon worked with them, and shared her experiences in how she started the Family Circle program. Yesodot, a JF&CS program similar to Family Circle and focused on Jewish families, is in its planning stages.

Though privacy regulations create a challenge, Reardon’s primary goal is to continue reaching out to many more families.

“The thing that scares me the most is that these parents feel so isolated. They need to know that there are other parents out there, who have been through this experience too. They will be more than happy to talk, to reach out and help you if you are in the same situation.”

For more information on Family Circle, please call Patty Reardon at 781-551-0405; or find us on the web at www.jfcsboston.org.
ENABLING DESCENDANTS OF SURVIVORS TO DISCUSS AND EXPLORE THE IMPACT OF THE HOLOCAUST ON THEIR OWN LINES IS THE PURPOSE OF LEGACIES

The agency's history of Holocaust outreach is a long one, going back to the 1940s, when displaced survivors of Nazi persecution of World War II were forced to emigrate. Many fled to Boston, and JF&CS of Greater Boston became involved in resettlement. Today, JF&CS Hakalab (a program of Holocaust Services) works directly with Holocaust survivors in a new stage of their lives, offering emergency financial assistance, homecare, assistance in claiming reparations and restitution, advocacy, and other services. Ellen Ogintz Fishman, LICSW director of Holocaust Services, which includes Hakalab and Legacies, says, "Since the inception of Hakalab in 1996, we have worked closely with nearly 800 survivors and responded to more than 3000 calls for information and referral. Our goal is to provide comprehensive services, with understanding and compassion."

Additionally, the JF&CS Center for Family Assistance helps Holocaust survivors with some financial assistance. Programs of JF&CS's Jewish Healing Connections have Holocaust survivors who participate in their programs. "After all of the terror and trauma they have been through, we can be their Jewish connection," says Marjorie Sokoll, M.Ed., director of Jewish Healing Connections.

What is it like for descendants of survivors?

"The children of survivors know that their parents suffered tremendously," says Stern. They also know that the survivors were deeply saddened by their experiences. As a result, many children of survivors carry that sadness."

Stern stresses that each person’s response is different. There are numerous ways that descendants are affected. Attitudes and needs also change greatly over the course of a descendant’s life. This stems from the wide range of responses of their parents, and how they may have handled the subject when their children were growing up. "Some parents talked more, some talked less; some were more emotional, others were withdrawn; many may have functioned very well on a daily basis," says Stern.

However, witnessing the survivors’ attempts to cope with their memories of the Holocaust can also have some positive outcomes for their descendants. "It can help them to be empathetic, and capable of recognizing other people’s pain," says Stern. "Many also feel a need to speak up when they see injustice around them."

Enabling descendants of survivors to discuss and explore the impact of the Holocaust on their own lives is the main purpose of Legacies. "One of our goals is to decrease the sense of isolation, and provide a comfortable setting for descendants to come together. They are often surprised when they realize how much they have in common with the other participants," says Stern.

"We recognize that the needs of descendants of Holocaust survivors are diverse. This is why we provide a variety of forums." At one end of the spectrum are films and lectures, followed by discussion, and one-time meetings in which participation is optional. At the other end of the spectrum are the eight-week support groups, which permit in-depth participation.

Susan Erony’s workshop was important for the work of Legacies, says Stern. "We are always looking for ways to use methods beyond speech and discussion. Art is a wonderful medium for finding new modes of expression. Participants had an opportunity to actively create something that had meaning for them."

For more information on Legacies, please call Dr. Ziva Stern at 617-558-1278. For information on Holocaust services, call Ellen Fishman at 617-558-1278. Or, find us on the web at www.jfcsboston.org
Jewish Family & Children’s Service
Fifth Annual Autumn Dinner and Auction
November 8, 2001, Four Seasons Hotel Boston

JF&CS’s Fifth Annual Autumn Dinner and Auction was another fantastic success. A sellout crowd enjoyed an entertaining evening, highlighted by the Live Auction, hosted once again by Susan Wornick of WCBV-TV5. Thanks to the generosity of our donors, the event raised over $325,000 to benefit JF&CS. We help over 30,000 people annually, with a wide range of programs serving people of all ages and faiths throughout Greater Boston.

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