Long Term Planning
What Have We Learned in 14 Years?
Leslie D. Park, Chairman of the Board

During the past 14 years, since the founding of Life Services, several hundred families have come to us for specific counseling and guidance on the basic question, “How can we best provide for the future care of our disabled sons or daughters when we are no longer here?”

More than 3,500 families, their attorneys and friends have written or called us for similar advice.

Over 5,000 individuals and organizations in 40 states and 6 foreign countries receive LifeLines, our regular newsletter, a publication designed to carry information on long-term planning (information only, we do not accept advertising of any kind.)

This is a summary of what we have learned over the years:

- There can be no “cookie cutter” approach to long-term planning. Each family, and each disabled individual within that family, has very unique needs.

- Most families have had very little or “poor” advice on matters of future planning for their disabled loved ones.

- A single meeting, either group or individual, is seldom adequate to answer all the questions about this important and complex matter. Long-term planning is a “process” which extends over a period of time and may involve a number of people.

- Although financial considerations are important, most families are concerned with the “quality” of care that will be available when they are no longer here. Adequate financing does not always guarantee quality services.

- All good future planning involves the use of a combination of resources from government, voluntary organizations, family and friends. Rarely does a single source provide everything an individual with a disability may need.

- All types of planning require a review and updating periodically.

- Uncertainty and procrastination are the biggest enemies of adequate long-term family planning. Lack of money is rarely the primary reason families put off planning.

- The assignment of a local Personal Advocate by Life Services for each member family has proven to be an effective way to serve persons with disabilities and their families throughout the United States.

- Reaffirmation has been made that this work should continue on a not-for-profit basis, rather than as a business.

Many additional lessons have been learned and integrated into our effective model of life planning. We continue to attract an ever-increasing number of families with disabled members.

The successful history of working with the present plan has encouraged the Board of Directors to undertake an expansion of the program. This will involve a greater geographic outreach* and the addition of new staff members, while maintaining the same high quality of service to all member families.

* Member families, disabled clients and Partnership Organizations are presently served in California, Florida, Georgia, Illinois, Louisiana, Maryland, Massachusetts, Nevada, New Jersey, New York, Pennsylvania, and Texas.
Parents of children with disabilities are usually the primary advocates for their children. Their advocacy typically starts when they identify their children’s disabilities and special needs. From that point on, in an effort to obtain the best quality of life for their children, parents are forced to become actively involved in decision making in multiple sectors. At each stage of their lives, parents monitor programs and progress; evaluate their children’s experiences; and develop and pursue strategies for their children’s special needs. The parents experience continuing pressure; they understand that special needs and service programs change, and they learn that they must advocate continually for their children in every area of their lives.

As parents grow older and confront the realities that accompany their own aging processes and mortality, the difficulties related to ensuring an appropriate and high quality future for their children with disabilities become increasingly apparent. Some parents have a family member or a special friend who will become the active advocate when they are no longer able to do so. Many parents, however, acknowledge that they cannot assume that those individuals who are designated as advocates will be able to be advocates for the lifetimes of their children. For many families, there are no individuals to assume responsibility for lifetime advocacy for the family member with a disability, so, they must find an organization on which the parents can depend to provide the advocacy that is essential for securing the future of their disabled loved ones.

The Life Services program has been designed to address the need for the individual advocacy essential for assuring the highest quality of life for individuals with disabilities when their parents are not able to provide it. Our nonprofit human service organization provides a Personal Advocate to perform two key functions for each individual being served: first, to work directly with the parents to develop the plans they need to provide lifetime advocacy for their disabled family member; second, to serve as the lifetime advocate for the person with a disability when the surviving parent dies or is unable to fulfill the role.

The future is unknown and no program can offer a guarantee. However, Life Services offers parents the opportunity to plan and prepare for a secure future of their children. Developed and refined over the last 15 years, working directly with persons with disabilities, families and professionals, this program responds to a widely held deep concern about the future for individuals with disabilities without parental advocates.

The Life Services program assumes that:

- planning can help to assure the quality of life for a person with a disability.
- lifelong advocacy is required to maintain the quality of life for a person with a disability.
- the person with a disability will participate in the planning process, to the extent possible.

If you are worried about the future of a disabled loved one, especially after you are gone, a Life Services membership will relieve some of your worries.

Our toll-free number is 800/995-0066.

We look forward to hearing from you.
WE ARE GROWING!

MEET OUR NEW DIRECTOR OF FAMILY SERVICES

We are pleased to announce that Tracy-Ann Adams has joined our staff as the Director of Family Services.

Tracy-Ann has over sixteen years of experience in both the social services and healthcare fields. Most recently, she served as the Director of the Child Health Plus and Family Health Plus Programs at Fidelis Care New York, a non-profit managed care plan that provides health insurance for uninsured children and adults throughout New York State. Previous healthcare experience includes three years as Assistant Director of Government Relations at Fidelis and five years as a Social Work Case Manager at Aetna US Healthcare. She also has several years of hands on experience as a caseworker for the Medical Assistance Program and as a counselor in a group home for disabled adults.

Tracy-Ann’s educational background includes a Master of Science in Health Services Administration from Central Michigan University and a Bachelor of Science in Human Development and Family Studies from Cornell University. Tracy-Ann’s primary responsibility as Director of Family Services is the recruitment, training and supervision of the Personal Advocates (formerly called “Client Advocates”) who are assigned to each member family. She is here to assure continuous quality service to all our members.

Tracy-Ann is a great match for us and our members because of her “heart,” that important quality that makes her an outstanding advocate and overseer for our members with disabilities; a trusted surrogate for our families; and a competent resource for everyone interested in life/future care planning and services for people with disabilities. Tracy-Ann states, “I feel honored to be part of a unique organization like Disabled and Alone and look forward to contributing to its mission to ensure that no person with a disability is subjected to a diminished quality of life when his or her family is not longer there to provide care.”

We know you will share our enthusiasm when you meet her. Why not do so today? Call Tracy-Ann (800/995-0066) with your questions, comments or just to say “welcome.”

OUR NEW PARTNER IN NEW JERSEY

Cerebral Palsy of New Jersey is a well-known and respected resource for finding help to solve problems related to education, employment, assistive technology, housing and advocacy for children and adults with temporary or permanent disabilities. The disabilities they serve include cerebral palsy, brain injury, spinal cord injury, spina bifida, mental retardation, stroke, hearing or visual impairments, learning disabilities, drug and alcohol illness, arthritis and others.

As a Life Services partner, Cerebral Palsy of New Jersey adds another service to its long list of programs, life planning, advocacy and care of individuals with disabilities. By providing this new service, CP of NJ will be able to help families ensure a high quality of life for their loved ones with a disability, especially when the families will no longer be around or are incapacitated.

Life Services is proud to announce this new association and looks forward to working with this outstanding organization.

For more information about this new partnership and to get a schedule of educational seminars in New Jersey, call us at (800) 995-0066.
A LETTER FROM A MEMBER

I first came to Life Services for the Handicapped in 1997. For two years, I paid a yearly fee. Their services were so impressive that in 1999 I enrolled in the Lifetime Care Service Plan. Where I am today, I would not be without their services. In July 2001, I entered the hospital unexpectedly. Life Services advocate, Karen Carpenter, took me to the hospital. She found respite services for my son, Doug. She even took my dog, Frisky, to the kennel. Roz Brilliant, Executive Director, came down from New York to visit Doug in the respite home and verify that Doug was in a respite home with good living standards. She has made a point of coming to visit and help us in South Jersey no less than twice a year.

Karen and Roz are truly my angels!!! A respite home is temporary, usually two weeks. Doug was there for one year. This had an adverse effect on Doug because he could not make a permanent friend. With the three of us working together we were able to find suitable placement for Doug. The association he is with has homes in North Jersey, Central Jersey, and South Jersey. The only opening for Doug was in North Jersey, 165 miles from my home. Now Roz, Karen and I are keeping in contact with the state supervisor hoping for an opening in South Jersey so that I can see Doug more frequently. It took the three of us (Roz, Karen and I) to make these events happen!!! As I said before I could not have done it alone.

Margaret Hancock, 2002

ANNUAL PARENT LUNCHEON

Our annual Parent Luncheon was held on December 13th at the United Nations Millennium Hotel in New York City, with 35 parents attending. This “complementary” gourmet luncheon is an opportunity for new and old members of Life Services to meet with staff and board members and to “air their concerns.”

A new Power Point visual presentation, compiled by the Life Services staff and highlighting important people and events in our history, was displayed during the luncheon. Tracy-Ann Adams, newly appointed Director of Family Services, had an opportunity to meet family members and describe her work and hopes for the future.

Roz Brilliant, Executive Director, brought us all “up to date” on current and future program activities.

Board members Rex Davidson, Robert Gutheil and Dr. Leon Sternfeld answered questions and expressed their pleasure at being a part of such a vital organization.

Les Park, Life Services Chairman, made a presentation entitled “Dollars and Sense”, stating, “No one should leave this meeting without fully understanding the costs and benefits of the Life Services program of long term planning for their disabled family members.”

The Parent Luncheon for 2003 is scheduled for December 5, 2003.

DANNENBERG GIFT HELPS CEREBRAL PALSY FOUNDATION

The estate of Louise W. Dannenberg, recently deceased Life Services board member and mother of Betty, who has Cerebral Palsy, provided two generous gifts to United Cerebral Palsy.

Betty presented an unrestricted gift of $100,000 to the United Cerebral Palsy Research and Education Foundation on May 31st. Mr. Paul Volcker, Foundation President and former Chairman of the Federal Reserve System, received the gift with gratitude at the Foundation’s luncheon meeting at the Harvard Club in New York City.

Mr. Leslie Park, Life Services Chairman and Founder, spoke of his long friendship with Louise Dannenberg and her enthusiasm for the Research Foundation’s activities, which were regularly reported to her.

Dr. Murray Goldstein, Director of the Foundation, reported on several of the Foundation’s projects at the meeting. The Foundation supports research targeted to the prevention of Cerebral Palsy and to improving the quality of life for persons with disabilities.

Betty Dannenberg presented another gift of $100,000 to United Cerebral Palsy of New York City for improved services to the disabled clients living in Belsky House in Brooklyn. The gift will provide additional outdoor facilities for the disabled residents of this 72 apartment unit on the UCP Rehabilitation Brooklyn campus.

Mr. Jerome Belson accepted the check and turned it over to Mr. Leo Hausman, Chairman of the UCP/NYC Board of Directors. Belsky House is named in memory of Mr. Belson’s father, a well-known civic leader in the greater New York City area.
On the evening of the worst snow storm in the New York area in the last several years, the Life Services Annual Leadership Award Dinner was held at the Marriott Marquis Hotel in New York City. More than seventy of the expected 125 guests made it to the dinner, slogging through ten inches of driving, wet snow – but what a grand evening it was!

Vice President Stanley Pinska, this year’s dinner chairman, started the evening off by welcoming friends and guests to the reception, as everyone watched the storm turn New York’s Times Square into a fairyland.

Master of Ceremonies Rex Davidson welcomed Reverend William Tulley, Pastor of St. Bartholomew’s Episcopal Church, who offered the Invocation. (Rev. Tulley is honoree Bob Gutheil’s Pastor.)

After a beautiful gourmet dinner of crusted salmon, the ebullient Executive Director of Life Services, Roz Brilliant, spoke about the organization as it passed its 14th birthday.

Paul Volcker, Guest of Honor and Chairman of the Federal Reserve Board from 1979 to 1987, was then introduced. He spoke of the work of the National United Cerebral Palsy Research and Education Foundation, which he now heads, and commended Life Services for its vision.

Following Mr. Volcker’s remarks, Roz Brilliant and Betty Dannenberg, the disabled daughter of benefactor Louise Dannenberg, presented the first annual Dannenberg Memorial Service Award to Peter Smergut, Executive Director of the Working Organization for Retarded Children and Adults (WORC) of Lake Success, New York. This new award is presented to an organization making a significant contribution to the betterment of the lives of adult people with disabilities.

Presentation of the Annual Leadership Award was then made to Robert H. Gutheil, Executive Director of The Salvation Army, Social Services for Children program in New York. “Bob” has been a member of the Life Services Board of Directors since its founding and is a nationally known and highly respected leader in child welfare services.

Lt. Col. William LaMarr, Regional Commander of The Salvation Army, assisted in the presentation and spoke of his high regard for Mr. Gutheil, both in his personal and professional activities. Lt. Col. LaMarr closed the meeting with the Benediction.

As always, the dinner was a warm and friendly affair and a “good time was had by all”!
OBITUARY

Rabbi Irving J. Block
Emeritus Rabbi of the Brotherhood Synagogue of Gramercy Park in New York, Rabbi Block passed away on October 31, 2002 after a long illness with Parkinson’s disease.

A founding member of Life Services, Rabbi Block was the recipient of our Leadership Award at the Millennium Award Dinner in 2000. His wisdom, humor and loyalty to our organization, and any effort designed to assist disabled people, were always effective. We extend our sympathy and “thanks for sharing him” to his wife, Phyllis, and son, Herbert.

Monsignor Thomas Cribbin
Father “Tom” never hesitated when asked to serve on the board of Life Services in 1989. Since the early days of his priesthood, when he demonstrated a special “heart” for the deaf and hard of hearing, his work and his spirit were focused on assisting people with disabilities and their families. For many years, he headed the disabilities department and its many programs for Catholic Charities of Brooklyn. He was an active and trusted advocate whose wisdom was sought by government officials and the wide community of organizations and agencies serving people with disabilities and the needy.

He passed away in Spring of 2002.

BACK COPIES OF LIFELINES

Since 1989, LifeLines has been published 2 or 3 times each year. Valuable information about life planning for a person with a disability has been included in each issue.

Write us requesting specific information and we'll send you the appropriate back copies without charge.

Specify such things as “About Life Services,” “Financial Information,” “Pooled Special Needs Trusts,” “How We’re Different From Other Plans,” etc.

FROM OUR CASE FILES

“THE PEOPLE IN CHARGE WHEN YOU’RE NOT THERE”

When Mrs. Jones died, leaving her grieving disabled son, John, in a group home, some remarkable things happened. Since Mrs. Jones had joined Life Services ten years ago, she had:

1. An experienced (and much loved) Personal Advocate for her son. This advocate, a woman John knew very well, was able to move in quickly to help him with his adjustment to the loss of his mother.
2. A good and up-to-date Will.
3. A carefully crafted and updated Special Needs Trust.
4. Funds for her son in the Life Services Pooled Special Needs Trust.

Mrs. Jones had considerable “human” resources in the organizational structure of Life Services. Here is how they worked upon her death.

Because Mrs. Jones had no living relatives, other than her disabled son, the Executive Director of Life Services was notified of Mrs. Jones’ death by the hospital. She immediately notified other staff members who mobilized for the burial and memorial service. The Personal Advocate was there to comfort the disabled son and arrange for his participation in his mother’s funeral and burial. Board members helped with many of the financial details and the Life Services attorney provided for necessary tax payments and assisted the trustees (designated in her Trust) in handling other affairs.

In short, it was an efficient and humane team effort. This true story demonstrates the effectiveness of having a skilled organization as a partner. A well-meaning relative often cannot mobilize resources as effectively. Life Services will now complete its responsibilities by seeing to it that John, although living in a wheelchair, will have the assets his mother left in his Trust contribute to his quality of life FOR AS LONG AS HE LIVES!

No, everything didn’t go absolutely smoothly, but the value of PLANNING by this caring mother was demonstrated in the humane and efficient program that supported her son at his time of need. John now anticipates a good quality of life with the help of a caring organization, Life Services, which both mother and son came to trust.

(Names are fictitious – events are true)

COMING TO NEW YORK?

Want to know more about what we do?

Why not schedule a no-obligation session with one of our senior staff members while you’re here?

We’re always there with a smile, lots of good information and a hot cup of coffee!
### A Quick Look At The Financial Picture

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<thead>
<tr>
<th>Life Services Contription</th>
<th>Family Contribution</th>
<th>Special Needs Trust Funding Options</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Staffing</strong></td>
<td><strong>Membership Fee</strong></td>
<td><strong>Pooled Special Needs Trust (3rd Party-Funded Trust with Life Services as the trustee)</strong></td>
</tr>
<tr>
<td><strong>Overhead</strong></td>
<td><strong>Annual Service Program Fee (optional)</strong></td>
<td><strong>Minimum contribution: $100,000</strong></td>
</tr>
<tr>
<td><em>Life Services</em> raises funds through independent fund raising activities.*</td>
<td><strong>Inter-vivos (while you are alive) or testamentary (through your Will) funding of the Pooled Special Needs Trust (optional)</strong></td>
<td><strong>No legal fees to set up or maintain the trust fund.</strong> OR</td>
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<td><strong>Individual Special Needs Trust (You choose the trustee)</strong></td>
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<td><strong>Your lawyer sets up the trust. Charges, legal fees and minimum contribution requirements may apply.</strong></td>
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**Administrative and Support Staff**
(Salaries, benefits, etc.)

*Life Services* covers 100% of all salaries and benefits for the staff through private fund raising activities and bequests from members and their families.

**Membership Fee**
The initial membership includes the following:
- **A Personal Advocate** who will facilitate the planning process.
- The **Planning Journal**.
- Counseling and advice on future planning for the person with a disability.
- Attendance at residential and program meetings and government hearings.
- Guidance and support when needed.
- Our newsletter, **LifeLines**.
- Invitations to meet other parents.
- The financial plan.
Cost: $3000 (one-time fee)

**Personal funds:** Savings and Investments*
Funds that transfer according to terms of a contract (assets with survivor’s benefits), such as an individual retirement fund or annuity, should designate the Special Needs Trust (SNT) as the beneficiary, not the individual, in order to preserve eligibility for entitlement programs.

**Inheritance and Gifts:** All inheritances or gifts from friends and family should be directed to the SNT and not to the individual. **
Trusts may be funded immediately (inter-vivos) or upon your death (testamentary) through your Will or survivor’s benefits, where funds are directed to the SNT.

**Office Administrative Costs**

*Life Services* covers 100% of all administrative costs for the office through private fund raising activities and bequests from members and their families.

**Pooled Special Needs Trust (3rd Party-Funded Trust with Life Services as the trustee)**
Minimum investment: $100,000 (see funding options)

**OR**

**Individual Special Needs Trust** set up through your lawyer with your own trustee.
Minimum investment: Varies

**Life Insurance:** The SNT is designated as the beneficiary of the policy.
There are many options, which vary in cost: Term Life, Whole Life, Universal Life, as well as “Second-to-Die” policies, which is a type of life insurance policy that insures two lives. The death benefit is payable at the second death. Also referred to as a survivorship policy. Speak to your insurance carrier to determine the best option for you.
Cost: Policy Premiums

**Property:** (such as a home or other property) may be left to the SNT through your Will.

*Through private fund raising, *Life Services* supplements the family contribution to cover services to its members.*

**Annual Service Program** (Option for those not in the Pooled Special Needs Trust who wish to continue services after the initial membership)
Cost: $3,000/yr. (Quarterly payment options available)

**Annual Service Program through Partnership Organizations** (where available)
Cost: $1,500/yr.

100% of the family’s contribution goes towards the cost of services provided for the person with the disability. The earned annual interest pays for the *Life Services* program.

*A Third-Party Trust cannot be funded with income or assets belonging to the disabled individual.*

**Administrative and fund raising costs account for only 1.82 % of our budget.**
(Based on 2001 data)

**It is important to advise all family and friends not to leave money or assets directly to the person with a disability, but rather to direct them to a SNT. This way, the gift is there for the person but does not affect their eligibility for entitlement programs such as SSI, public housing and Medicaid. Many programs have income and asset limitations for eligibility. Money in a SNT is not counted as a resource for the person with a disability, so it will not affect the eligibility determination.**
WHY NOT BECOME A REGULAR CONTRIBUTOR TO LIFE SERVICES

Some of our contributors tell us that it is easy to contribute small amounts to Life Services when they pay their bills on the first of the month.

Why not consider this method! If you ask for them, we’ll send you 12 postage paid envelopes for monthly contributions.

Simply call us at 1-800-995-0066.

CALENDAR OF EVENTS

Educational Programs
YAI Annual Conference, NYC May 6-8, 2003
ACPOC Annual Conference, FL May 15, 2003

Personal Advocate Training Seminar
Session 1 May 2, 2003
Session 2 Oct. 3, 2003

Annual Parent Luncheon