

LIFELINES



Disabled and Alone/Life Services for the Handicapped, Inc.

Summer 2003



Left to Right - Tracy-Ann Adams, Director of Family Services; Mayor Bloomberg; Leslie D. Park, Chairman and Founder; John Wingate, Life Services Board Member

Mayor Bloomberg

On April 14, 2003 Life Services Board and staff members attended a reception hosted by the Mayor of New York City, the Honorable Michael R. Bloomberg, in honor of Disabilities Awareness Month.

Mathew Sapolin, Executive Director of the Mayor's Office For People With Disabilities, organized the event, which was held at Queens College.

In March, a formal presentation about the Life Services program was made to the staff of the Mayor's Office, thus helping them provide useful information for families worried about the future of a loved one with a disability.

Membership Pace Grows

With the acceptance of eight new "members" in the first few months of 2003, *Life Services* is seeing a rapidly growing "pace" of activity and interest. Interviews with prospective members, family members and attorneys now average four or five a month.

Life Services requires that a senior staff person visit the person with a disability before accepting him or her for membership. This policy assures that *Life Services* can really be helpful to the person. There is no point to a membership if the family's goals and the person's needs cannot be met.

After a formal membership, that is, signing an Agreement and paying the membership fee, each new family is matched to an appropriate local *Personal Advocate* to guide them through the planning process, which may take a year or more and includes completing the *Planning Journal*.

As more families with a disabled member realize the importance of long-term planning for their special family members, we expect the future pace of service to continue to grow.

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Disabled and Alone/Life Services for the Handicapped, Inc. is a not-for-profit organization founded in 1988 whose sole purpose is to assure the well being of disabled individuals, particularly those whose families wish to plan for the time when they will no longer be able to provide care.

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Roz's Remarks

Opportunities For Grandparents

This has been a week of calls from grandmothers. As a result, I will devote this column to the many loving grandmothers (and grandfathers, too) looking for ways to help their special needs grandchildren.

Let me share two of the calls:

The first call was from a California grandmother, Trudy, who asked many questions about *Life Services*, trying to understand how our program might help her 16-year-old learning-disabled grandson, Christian. Trudy explained that Christian's parents take wonderful care of him, but just do not have the time to think about planning for his future. She told me that her daughter and son-in-law hold full time jobs, and spend their evenings helping Christian with his homework after taking him to a psychiatrist, psychologist, reading tutor, math tutor and basketball at the local YMCA. Trudy is preparing her own will and other legal documents, having recently been widowed, and wants to get her estate in order while she is well and can make good decisions.

Trudy and I talked a long time about the benefits of *Life Services* and a Special Needs Trust. She was delighted to learn that there was a way that she could "still be around" to help Christian (and his parents) after she's gone.

The second call came from a New York grandmother, Bess, who is dealing with some serious medical problems. Before she dies she wants to leave \$10,000 for her disabled granddaughter, Elaine, in the *Life Services Third Party-Funded Special Needs Trust* (that is, our Pooled Special Needs Trust -- PSNT). I explained to Bess that our minimum funding for the trust is \$100,000. Bess responded by asking if she could leave \$10,000 to the trust and have her son and daughter-in-law make up the difference by purchasing a life insurance policy. Bess was really searching for a way to safeguard Elaine's future and leave a gift for her beloved granddaughter.

After speaking with Bess, I called an attorney to ask about Bess' idea. The attorney explained that if Elaine inherits money directly from Bess, it could not be placed in our PSNT, since it will then be Elaine's money and our trust cannot accept money from a person with a disability. The money would have to go into a self-settled Special Needs Trust, created by a private attorney, which would be required to pay back Medicaid when Elaine died. He added, however, if Bess signs the PSNT Sponsor Agreement and leaves \$10,000 to the PSNT and Elaine's parents agree to purchase a life insurance policy naming the trust as the beneficiary and covering the difference, then Elaine's family could participate in our PSNT. He added, however, that under these circumstances, services would not begin until the trust was funded with at least the minimum amount, but the \$10,000 would appreciate in the interim. Bess was quite pleased to learn that our program is flexible enough to allow her to use it.

I write this article to help the many grandparents who would love to provide, upon death or while they are alive, for a special needs grandchild, without jeopardizing government entitlements and programs.

Grandparents, if you have a special situation that you wish to discuss, do not hesitate to call us.

We're here to help.



Investment Standards For Charities

In these times of high volatility in the money markets, it is difficult for an individual or an organization to know how and where to invest money.

Charitable organizations are under constant scrutiny by a variety of state, federal and local agencies set up to monitor the work they do, particularly in matters of money management.

For many years, the “prudent man rule” dictated policy. This regulation simply tests whether the organization “is handling other people’s money the way a prudent man would.”

Life Services has an Investment Committee, made up of members of the Board of Directors, who meet regularly to recommend to the board policies affecting money management. Safety, liquidity and return, in that order, are the goals of all *Life Services* investments. Investment changes are made from time to time, as conditions warrant, but the Committee always asks, “Is this what a prudent man would do?”

In recent years, we have found that our investment practices have been very sound, but “management” means constantly evaluating conditions and making changes as necessary.

Not-for-profit corporations must strictly adhere to and regularly examine their compliance with the laws governing investments by nonprofits. A recent variation in the New York Not-for-Profit Corporation Law (HPCL #717) states that “directors and officers shall discharge the duties of their respective positions in good faith and with that degree of diligence, care and skill which ordinary prudent men would exercise under similar circumstances in like positions.”

The March 2003 publication of the New York Community Trust, Standards for Trustees and Executors, describes the new standard, which supercedes the “prudent man rule,” as follows:

Under New York’s former “prudent man rule,” the appropriateness of each investment was determined separately. If an executor or trustee bought an asset and it decreased in value, it could have been considered an imprudent investment even if the overall portfolio did well.

The Prudent Investor Rule makes it clear that there are no investments that are inappropriate or imprudent per se; it stresses the investment of the entire fund, as opposed to each individual asset, and the conduct of the fiduciary rather than the performance of the portfolio. The executor or trustee is expected to “exercise reasonable care, skill, and caution to make and implement investment and management decisions as a prudent investor would for the entire portfolio taking into account the purposes and provisions of the governing instrument.”

What Governmental Budget Problems Mean to Us (and to You)

The media have been full of reports and conjecture about the cutbacks in services made necessary by worsening deficits in all levels of government. How will these cutbacks affect services to families of children with disabilities?

It is clear that today’s strained budgets are likely to continue for a number of years. How this plays out in each community may differ, nevertheless, the following are likely to be some of the effects:

- Fewer group homes being staffed and built throughout the nation
- Reduced funds to voluntary non-profit organizations for programs of every kind (e.g., day programs, Medicaid, transportation and vocational training)
- Lower subsidies for special education
- Longer waiting lists for services
- Little or no building of new facilities
- Greater financial responsibilities on families with a disabled member to pay for needed services

At this time in our history, it is not a bright picture as we look to public programs for people with disabilities and their families.

The good news is that *Disabled and Alone/Life Services for the Handicapped* has never asked for or received governmental assistance of any kind and is not affected by the current cutbacks. This is not to say that we are immune from the general downturn in the economy as a whole, however, it is reassuring to know that the long-term care of the individuals with disabilities for whom our member families have done the necessary planning will not be unduly affected by current economic difficulties.

Leslie D. Park, Chairman of the Board

D o You Have A Question? Concern? Comment? Referral? Request?

You can now reach us online or by email. Of course, the telephone is still a good way to speak with us. Our toll-free number is (800) 995-0066.

Contact any one of us at the email addresses below and we will respond without delay.

Info@disabledandalone.org (General questions and requests for information)
Rbrilliant@disabledandalone.org (Roz Brilliant, Executive Director)
Tadams@disabledandalone.org (Tracy-Ann Adams, Director of Family Services)
Lpark@disabledandalone.org (Leslie D. Park, Chairman and Founder)
Kibrahim@disabledandalone.org (Kathy K-Ibrahim, Administrative Assistant)

C heck Out Our New Website!

Now *Life Services* is available to you 24 hours a day. Visit online at www.disabledandalone.org. See the FAQs page. It may provide an answer to your question or concern.

Use the site to:

- Find out more about us
- Request information
- Communicate with us
- Find answers to questions
- Make a donation

Y ou Can Now Support The Good Work At *Life Services* Online!

Our new website provides a simple way for you to help the needy families we serve. Just log on to our website at www.disabledandalone.org and click on the  key.

A Message From Our Director Of Family Services

Tracy-Ann Adams



Aging Caregivers

One can't help but notice how the popular press and other media are discovering the problems of caring for disabled family members. I recently found an article on the web by Tamar Heller, Ph.D. and Alan Factor, Ph.D. of the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois, which estimated that 60% of individuals with mental retardation live at home and are receiving their primary care from their families. It is estimated that in 25% of these households, the family caregiver is 60 years of age or older and the average age of the person with the disability is 38 years old.

The aging parent caregiver is a new phenomenon. As a result of advances in medical science and overall better lifestyles, people with disabilities are living longer; consequently, the care giving responsibilities for the families are also extended. As the life expectancy of people with disabilities increases, the need for support services to help the aging caregivers has also increased; however, the funding for these services has not kept pace with the need. Although there has been an increase in funding for family support programs in the past ten years, oftentimes the funds are targeted to families with young children and not the older population.

According to the article, older family caregivers identified several areas in which they feel their services needs were not met. They include information on residential programs, financial planning, guardianship and respite services. One can only hope that with this new focus on the problems faced by family caregivers, funding for support services will shift to alleviate the burden on aging families.

Personal Advocates: *Our Frontline Team*

An integral part of the *Life Services* model is that of the *Personal Advocate*. When a family joins *Life Services*, a *Personal Advocate* is carefully selected to work with the new member. The Personal Advocate brings years of educational, professional and life experiences to the role, as well as compassion and commitment to the member being served. The Advocate becomes the voice for members who cannot advocate for themselves and makes every effort to assure that each member has an enriched "quality of life" and is never lonely and isolated.

The *Personal Advocates* assist our members and their families in identifying the future needs of each person with a disability and, then, incorporating them into a lifetime care plan. During this period, the *Personal Advocate* develops a first hand understanding of the family's wishes and the individual's special needs.

Once the plan is implemented, the *Personal Advocate* keeps in contact with the member through regular visits and phone calls, and by attending residence and program meetings (where appropriate).

The Advocates' goal is to ensure a high quality of life for the members. They not only focus on the "bread and butter" issues, such as the living environment, personal hygiene, financial management, recreational and social needs, medical and dental care and social service needs, to name a few, but they also are there to celebrate birthdays, go out for a meal, participate in social functions, provide support, handle emergencies and other activities which help improve the life of the individual with a disability.



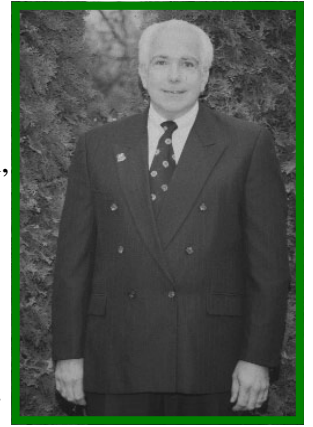
Because of their expertise in the field, our *Personal Advocates* are often asked to step in when a problem arises. Our members grow to trust and rely on them, but most of all, the Advocates become "one of the family." For families that oftentimes do not have anyone to turn to for help, the *Personal Advocate* provides the family with some peace of mind and the knowledge that the family is not alone and has someone to call on when needed.

Meet Board Member – Wells B. Jones

The future of *Disabled and Alone/Life Services for the Handicapped, Inc.* is in the hands of its Board of Directors. It is this group of people, meeting regularly to guide the organization, who assure its permanence and financial health.

Life Services is extremely fortunate to have a very dedicated, well-respected and competent Board. We plan to introduce you to its members by featuring them, from time to time, in *LifeLines*. In this issue, we have the pleasure of telling you about Wells B. Jones.

Wells B. Jones, CAE, CFRE, has served on the *Life Services* Board of Directors since 1991. He is a nationally known leader in the nonprofit field and the Chief Executive Officer of *The Guide Dog Foundation of Long Island* in Smithtown, New York.



Under Wells' leadership, *The Guide Dog Foundation of Long Island* has experienced major financial and service growth. This year, the organization will complete a significant building program, putting it in the forefront of international dog training facilities for people with visual impairments.

During his tenure on the Board, Wells brought *Life Services* into the *Neighbor to Nation* division of the Combined Federal Campaign and he currently serves as the Chairman of the Board of *Human Service Charities of America*, a major section of *Neighbor to Nation*.

Wells' past experience was in fund-raising, where he worked on behalf of *United Cerebral Palsy of New York City*, *Holy Family Hospital of Des Plaines*, Illinois, and the Epilepsy Foundation.

In 1985, the Long Island Chapter of Fund-Raising Professionals honored Wells at its annual conference by recognizing him as the Outstanding Fund-Raising Executive for that year and in 1994, the New York Society of Association Executives named him Outstanding Association Executive. He currently holds several major positions with the American Society of Association Executives.

A warm and personable individual, with a real heart for people with disabilities and their families, we are pleased, proud and enriched to have Wells on our Board of Directors.

Fund Raising Opportunity



Talk to your mail carrier about *Disabled and Alone/Life Services for the Handicapped*, #2828 in the Combined Federal Campaign (CFC) Directory of Charities.

Each fall, all federal employees and members of the armed services (3.7 million people) participate in the CFC to support approved charitable nonprofit organizations.

Disabled and Alone/Life Services has been one of the charities in the program for nine years. Each year, the United States Office of Personal Management carefully reviews our application and approves the work of our organization before authorizing our participation in the CFC.

If you would like to help in this fund raising effort, please talk to your mail carrier (who is a federal employee) and ask him or her to consider designating and supporting *Disabled and Alone/Life Services for the Handicapped* with a contribution in the fall 2003 campaign. You might even ask him or her to mention us to co-workers.

Most federal employees are happy to learn about worthwhile organizations through the people they serve.

Our CFC number is 2828. Thank you for your help!

But I Want My Money To Help My Disabled Son Or Daughter When I'm gone!

Every mother and father of a child with a disability makes this statement – or thinks it. It's easily said – but not easily done.

In this and subsequent issues of *LifeLines*, we will try to deal with the major issues around this question. We invite your comments and personal experiences by letter or email.

Bequeathing money or assets, such as stocks, bonds, real estate or an insurance policy, can be a major problem for a family with a disabled member. A straightforward gift in a Will would seem the simplest way to handle this issue, yet, consider the following:

Money left in a Will must go through Probate Court, sometimes a lengthy process.

If assets are directly passed on to an individual with a disability, he or she will most likely be disqualified from public (government) entitlement programs.

He or she could lose:

- Medicaid.
- Supplemental Security Income (SSI).
- Public or subsidized housing.
- Food Stamps.
- eligibility for programs provided by voluntary organizations.
- work incentive programs.

Some individuals with disabilities are not able to handle their own funds and could spend an inheritance irresponsibly, without enjoying any long-term benefits from the gift.

Individuals with disabilities are often the target of fraud and/or a "con".

The best alternative for passing on funds for the benefit of a person with a disability is to create a trust, preferably a Special Needs Trust, where funds left by a third party, can be administered by one or more trustees. The question then becomes, "Who will be the trustee(s)?" or more simply, "Who can we trust to carry out our wishes for the future care of our disabled family member with the money we leave?"

Families facing this question normally think of a close family member, who knows and is apt to outlive the person with a disability, to serve as a trustee. Unfortunately, a brother or sister, or other relative, has his or her own life to live and may move to other parts of the country, may marry or divorce or may make life changes, which might mitigate against fulfilling the responsibilities of a trustee.

The best scenario ...

Life Services has found that a Special Needs Trust which names a responsible nonprofit individual as trustee, along with a sibling or relative trustee, makes for the best plan in administering a Special Needs Trust.

Life Services has a policy that makes it possible for the Executive Director of the organization or her successors to serve as a trustee in an approved Special Needs Trust, that is, one created for a *Life Services* member and funded to cover program requirements.

How long has it been since you reviewed and upgraded your Will?

***Life Services* recommends that you review all your legal documents at least every 3 years.**

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We estimate that there are at least 500,000 people born with a major disability who, after age 21, continue to live with their families.

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Major federal entitlements for persons with disabilities who qualify:

1. SSI (Supplemental Security Income)
2. Medicaid or Medicare
3. Food Stamps
4. Work Training
5. Public Housing
6. Social Security Disability Assistance