



SPRING 2010

# PLAN OF PA **Network News**

Quality of Life

Increased Independence

Financial Stability

## Estate Planning for Parents of Children with Disabilities

By Thomas D. Begley, Jr.

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**H**arry, 48, and Sally, 46, have an autistic son, Bill, age 21. Bill lives with his parents. The couple is concerned about Bill's welfare after they die. Harry and Sally always thought that Bill would live with his sister, Joan. Joan has three children and it is apparent that Joan's husband, Andy, will not be happy with Bill living in his home.

Harry and Sally have a home, retirement plans, and \$100,000 in investments. They have life insurance. Bill receives SSI and Medicaid, and he can have no more than \$2,000 of assets. Any income Bill receives will reduce his SSI benefit dollar-for-dollar, and if he loses his SSI, he loses his Medicaid. Bill would be eligible for a group home.

Like all parents of children with disabilities, the critical question in Harry and Sally's mind is, "what will happen to our child after we die?" Families are fearful that, after the parents die, there will be a

loss in the quality of life of the person with disabilities. The child will lose his parents as his most effective advocates, his parents' financial resources, and the child's lifestyle in the parents' home.

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From a legal and financial standpoint Harry and Sally are anxious about how to protect Bill in the future.

### The Start

The first problem is finding a lawyer who specializes in estate planning for persons with special needs. Most lawyers write Wills. Very few of these

lawyers have expertise in public benefits and disability law. One way to find a specialist is by asking a friend, another way is to go to [www.specialneedsalliance.com](http://www.specialneedsalliance.com). This is an organization of leading elder and disability law attorneys located throughout the country.

### The Special Needs Trust

Special needs trusts are discretionary, spendthrift trusts created for persons with disabilities which are intended to supplement, but not replace, any public benefits that the trust beneficiary receives.

They learn that a special needs trust is designed for persons with disabilities receiving SSI, Medicaid, Section 8 Housing or other public benefit programs. Harry and Sally's special needs trust will maintain Bill's SSI, Medicaid and potential eligibility for a group home in the future. At the same time, the trust will enable Bill to take advantage of the future

PLAN of PA provides ongoing care, now and in the future, for people with special needs.

Serving adults with mental disabilities and their families.



## PLAN OF PA

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inheritance that Harry and Sally will leave for his benefit.

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*The special needs trust maintains Bill's SSI, Medicaid and eligibility for a group home, and enables him to take advantage of the future inheritance.*

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The trust fund can be used to pay for services and equipment that Medicaid would not cover. The special needs trust could purchase a home, special wheelchairs, handicap-accessible vans, mechanical beds, as well as pay for vacations, a personal attendant, and recreational and cultural experiences. This trust will be specifically tailored to enrich Bill's life.

### Funding the Trust

Harry and Sally must decide how much money to put in the special needs trust. Parents often divide their estates equally among their children. If all of the children are healthy, this makes sense. If one child has special needs, that child may need more or

less than an equal share.

The best way to make that determination might be to have a life care plan designed for Bill. Harry and Sally would define the lifestyle that they want for Bill and the life care planner would estimate the cost of Bill's care over his lifetime. Harry and Sally could determine how much of their estate to leave to Bill's special needs trust. Once the life plan is analyzed, it may reveal that the assets in Harry and Sally's estate are insufficient to provide for Bill and his sister, Joan. In that case, Harry and Sally may consider buying a second-to-die life insurance policy. On the death of the survivor of Harry and Sally the insurance proceeds would be paid in to Bill's special needs trust. Joan may then receive a larger share of the other assets.

### Selecting the Trustee

A critical part of the special needs trust process is the selection of an appropriate trustee. The role of the special needs trustee requires a long term commitment, a keen sensitivity to the individual's disabilities, involvement in monitoring the individual's services, advocating for medical and financial

entitlements, and prudently investing and distributing the trust funds.

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*A professional trustee can invest money, comply with SSI, Medicaid and tax laws, and navigate the disability system.*

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The trustee also has to comply with a number of very complicated laws, including SSI and Medicaid law. A professional trustee should always be considered, because they have the ability to invest money, understand and comply with SSI, Medicaid and tax laws, and navigate the disability system.

### SSI

The Supplemental Security Income (SSI) program of the Social Security Act is a minimum monthly cash payment for persons with disabilities. The federal benefit is \$675 per month. Pennsylvania has a small state supplement. A person receiving SSI also receives Medicaid, which pays for medical expenses. ●

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Planned Lifetime Assistance Network of Pennsylvania (PLAN of PA) is a private non-profit 501(c) 3 organization dedicated to serving adults (18+ years of age) with mental disabilities – including mental illness, mental retardation, brain injury, and autism – and their families in the greater Philadelphia area. We provide fee for service Case Management, Trust and Representative Payee services in Bucks, Chester, Delaware, Montgomery and Philadelphia counties.

## PLAN of PA Services

### Case Management *Best Possible Quality of Life*

PLAN of PA fee-for-service case management seeks to improve lives by working with each person to develop a support network unique to his or her needs – encouraging independence, stability, and security while enhancing quality of life. Our private case managers maintain a flexible approach, with a focus on individual strengths. We assist clients in finding housing, managing their finances, and coordinating transportation and recreation opportunities, as well as monitoring personal needs.



### Trust Services *Financial Stability*

The PLAN of PA Special Needs Trust for the Mentally Disabled allows the establishment of an account for the benefit of a person with a disability. This trust account can pay for supplemental needs while at the same time protecting government benefits such as SSI (Supplemental Security Income) and Medicaid. This is made possible by an act of Congress, The Omnibus Budget Reconciliation Act of 1993. Common purchases by a trust include computer/electronic equipment, transportation costs, counseling/therapy, medical expenses and clothing. ●

To find out more about our services, go to [planofpa.org](http://planofpa.org), or call us at 610-687-4036.

## Executive Director's Message

# Our New Face in the Community

I'm sure you have noticed the new look of our newsletter. We changed the layout, printed it on different paper and invited a guest author to write the main article. This is all part of our strategy to reach out to the community to a greater degree and inform the public about what we offer in the way of case management and trust services to adults with mental disabilities. A key piece of this strategy is to have a newsletter that, in addition to providing information and news to our current clients, can be used to increase awareness of our organization to prospective clients.

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In the coming year, the Board and staff will continue to reach out to the community to increase the visibility of PLAN of PA through in-person events and increased circulation of our newsletter. Our newsletter will be another face in the community for PLAN of PA, providing information to the many people who are unfamiliar with our organization and are in need of our services.

We will continue to write articles that will be of benefit to our current clients; seeking out topics that will help families as they explore services and search for information to improve the quality of life for their loved one. We are open to ideas for articles and opportunities for public presentations. If you know of a group or event that might be interested in hearing about PLAN of PA, please feel free to pass that information on to us. ●

In all ways and all circumstances, PLAN of PA promotes acceptance and respect for individuals, and models a positive, "see beyond disability, see the strengths" perception of mental illness to the whole community.



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## Client Corner

# Estate Planning with Grace

Grace is a 47 year old woman with a severe anxiety disorder. Over the years, she has been unable to locate and maintain employment due to her disability. She lives with her parents and receives SSI (Supplemental Security Insurance) and Medicaid. In addition, Grace is on a waiting list to receive a Section 8 housing voucher. Grace's mom and dad, Ellen and Steve, came to PLAN of PA two years ago to put future plans in place for her. Grace has a brother in the Philadelphia area and a sister in Arizona. Each has families of their own and their parents do not want the full responsibility of Grace's care to fall on them.

An individualized and comprehensive Personal Care Plan was developed. Case Man-

agement services through PLAN were clearly defined. In addition, it was agreed that if Grace was unable to manage her finances, PLAN could become her Representative Payee for Social Security benefits. After careful research, Ellen and Steve opened a Special Needs Trust at PLAN of PA, which will be funded through life insurance policies and sale of property after both pass away. Grace's benefits will remain in place and the trust funds will be used for her supplemental needs. Grace, her parents and siblings have expressed a sense of relief that these plans are in place for the future. A PLAN case manager keeps in touch once a year to update information and remains available to offer services at the request of the family. ●

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