



PLAN | NJ NEWS

The Newsletter of Planned Lifetime Assistance Network of New Jersey

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Spotlight on Services

Like most people, Shannon* is fond of spending time with friends, participating in community activities, shopping, and is often seen enjoying a cup of coffee. Shannon's story has a happy ending. The endearing 48-year-old lives in a group home where she has met many new friends, attends a program at an adult training center where she earns money and also enjoys playing bingo during her free time. She has more social opportunities than ever before.

Unfortunately Shannon's family did not plan for her future care. Two years ago her mother became critically ill and passed away, and this new chapter in Shannon's life began. "In emergency situations such as these, Shannon was referred to the New Jersey Department of Health and Senior Services' Adult Protective Services division," explains PLAN/NJ Executive Director Ellen Ball Nalven. "Shannon came to us through the courts which is not an ideal situation. Luckily we were able to act quickly and an emergency guardianship was approved."

Within several weeks of Shannon's guardianship transfer to PLAN/NJ, it was discovered that she needed to undergo major surgery. The team at PLAN/NJ reacted quickly and a program service coordinator accompanied Shannon to the hospital, was there for her during recovery and subsequently coordinated her rehabilitation. After surgery Shannon was in need of new living arrangements. With the assistance of the Division of Developmental Disabilities, PLAN/NJ was able to secure a suitable group home for her to live.

Shannon recently attended a special dinner where she received an achievement award. Shannon's surrogate family at PLAN/NJ is looking out for her and making sure she is thriving in all areas of her life – at home, work, and socially.

Everyone wants the best possible care and future for their loved one and we know that there is no greater advocate for persons with disabilities or mental illness than family. But when circumstances require that families need assistance in this effort, PLAN/NJ can help. We offer advocacy and monitoring services, guardianship, life planning assistance and referrals to government agencies, financial planners and attorneys who understand the issues involved.

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Who will care for your loved one when you are gone? Plan now!

Psychiatric Advanced Directive

What is it? How does it work?

By Thomas D. Begley, Jr., Esquire

Psychiatric Advanced Directives (PADs) are legal documents similar to advanced directives given in connection with end-of-life decision making. However, PADs are used to give instructions with respect to preferences for future mental health care treatment. They can also be used to designate a proxy decision maker. A number of states have enacted PAD legislation. In some states, such as Wisconsin, a Power of Attorney may not be used to authorize mental health treatment.

Frequently, PADs are used to request or refuse specific treatment, such as any types of medication and other mental health interventions, use of physical and chemical restraints, release of information for treatment, participation in clinical trials of experimental treatments, hospital selection, and other directions to manage the person's routine responsibilities.

Advantages of Advanced Directives

The advantage of a PAD is that the individual can assume control over future health care treatment decisions. They are useful in communicating preferences to family members and providers. They may also facilitate appropriate and timely treatment interventions before situations deteriorate to emergency status. Utilization of PADs may lead to a reduction in adversarial court proceedings involving involuntary psychiatric treatment. Some states do not allow agents to make decisions in regard to psychiatric care; instead, court proceedings are necessary if the treatment is not voluntary.

Legal Capacity

There are two points in the PAD process in which legal capacity is an issue:

1. Execution. At the time the individual drafts and signs an advanced directive, the person must be competent. Most states presume that persons are competent at the time the advanced directive is executed. Also, most state statutes require that the PAD be signed by two adult witnesses who attest the person's capacity at the time the instrument is drafted.
2. Utilization of Document. At the time the document is used for health care or psychiatric decisions, the person must be incompetent to make those decisions for him or herself. Some states require that a court make capacity determinations at the time the PAD is utilized. Other states, such as Oregon, provide that determinations may be made by either a judge or two physicians. Since one of the goals of PADs is to avoid court involvement, the Oregon approach is preferable.

Refusal of Treatment and Override

There is a controversial issue concerning the use of PADs to refuse all treatment. Most state laws provide that an individual may use a PAD to consent or refuse psychiatric treatment.

Under what circumstances can a PAD be overridden? There have been no court decisions yet on when a PAD may be overridden, but it is likely that a PAD authorizing treatment refusal would be overridden if the individual was determined to be dangerous to him or herself or others.

Revocation

So long as an individual is competent, he or she clearly reserves the right to revoke a PAD. If the individual is actively symptomatic and in need of treatment, the issue becomes murky. A court hearing may be required in individual cases.

The National Alliance for the Mentally Ill (NAMI) suggests that an "Ulysses clause" be considered. Under a Ulysses clause, an Advanced Directive instructs treatment providers about specific treatment preferences, and explains that any statements made refusing treatment during periods of incapacity should be ignored.

Interest in Advanced Directives

A recent study of mental health consumers in public health treatment settings (in five states) showed that only 4% to 13% have completed a PAD. However, between 66% and 77% of those consumers say that although they currently do not have a PAD, they would want to complete one if they had the necessary assistance. The study showed that there were likely to be more interest in PADs when the following factors were present:

- Past adverse experiences with treatment pressures
- Social disempowerment
- Degree of insight into their illness and need for treatment
- Existence of social resources, including marriage

Registration

New Jersey is in the process of establishing a registry where PADs can be registered. Vermont and Washington State have established registrations for all advance directives through the U.S. Living Will Registry.

For more information about Psychiatric Advanced Directives, visit the New Jersey Department of Human Services website at <http://www.state.nj.us/humanservices/dmhs/>. A link to a sample PAD format can be accessed from the home page. Individuals can draft their own PAD's if desired. In order to register a PAD, the original must be mailed to: NJDMHS Registry, 50 E. State St, PO Box 727, Trenton, NJ 08625-0727.

Spotlight on Services

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The Importance of Planning Ahead

Although it is difficult to think about the care of a loved one after you are gone, Shannon's story is an important one. Shannon was lucky that she became a part of the PLAN/NJ family but many individuals are not so fortunate. PLAN/NJ was well equipped to jump in and assist Shannon because of our state, community, and local connections. If a LifePlan were established for Shannon, her future would have been mapped out and not left up to chance. Taking the first step in planning for the future of your loved one is difficult and uncomfortable but it is half the battle. If you would like more information about how to develop a Life Plan for your loved one, call us at (908) 575-8300.

**name has been changed to maintain client confidentiality*

Guardianship Services Offered by Stellar Organization

Throughout the state of New Jersey there are many organizations who offer a level of support and care that we believe represents the best that the community has to offer. We are delighted to inform you of one such organization serving primarily Hunterdon County - Volunteer Guardianship One-on-One.

They provide compassionate and complete guardianship services to adults who have no willing family members or friends, and who have been determined by the court to be in need of such personal services. Volunteer Guardianship One-on-One offers a program of recruitment, training and continuous support to their cadre of dedicated community volunteers. These trained volunteers are supported by significant professional and community resources and provide lifetime guardianship services to those in need with great care and personal compassion.

For more information visit their website at www.volunteerguardianship.org or contact Claire Boland, Education Coordinator at (908)284-9100.

ADA Act is Opening Doors...Again

It has been 18 years since the Americans with Disabilities Act was signed into law in July of 1990. Since that time many doors have opened for individuals with developmental disabilities and mental health challenges in the areas of employment, federal funding, communication, transportation and navigation through mainstream society. On September 25th the President signed the Americans with Disabilities Amendments Act of 2008, continuing to protect the rights of those we care for and love.

The bill will overturn several Supreme Court decisions that reduced protections for people with diabetes, epilepsy, heart disease, mental health challenges and cancer – who were originally intended to be covered by the ADA.

The ADA Amendments Act will become effective January 1, 2009. For more information on the important changes to the Act, visit the web at http://www.eeoc.gov/ada/amendments_notice.html.

Make Note...

Three organizations serving individuals with disabilities have recently changed names:

- NJ Protection and Advocacy (NJP&A) is now *Disability Rights New Jersey*
- COSAC or Center for Outreach and Services for the Autism Community has changed their name to *Autism New Jersey*
- Cerebral Palsy of New Jersey (CP of NJ) is now called *Advancing Opportunities*



*Lifetime Advocacy for People
with Differing Abilities*

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We're on the Web!

Visit us at:

www.plannj.org

For more information about PLAN/NJ, to schedule a presentation for your group or for help with planning for your relative's future, call: (908) 575-8300.

PLAN/NJ FUNDERS

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- The IOLTA Fund of the Bar of New Jersey
- The New Jersey State Bar Foundation
- The Hyde and Watson Foundation
- The Fred C. Rummel Foundation
- The Community Foundation of NJ
- National Starch & Chemical Foundation, Inc.

Looking for a specialist in Estate or Financial Planning for Individuals with Disabilities?

Inside you'll find a convenient pull out that lists the names and phone numbers of dozens of our Professional Sponsors who are attorneys or financial advisors. Whether you use it now or place it with your important papers for later use, you'll be glad you have it.