



# PLAN|NJ NEWS

THE NEWSLETTER OF PLANNED LIFETIME ASSISTANCE NETWORK OF NEW JERSEY  
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**Who will care for your loved one when you are gone?**  
**PLAN NOW!**

## PLAN/NJ Client Among Artists to Display at Local Gallery

At the Riverfront Renaissance Center for the Arts on N. High Street in Millville, you can find the work of local and regional artists throughout four galleries. Among these beautiful acrylic and watercolor paintings is the work of local artist John Miller. After taking art classes for only five years (most recently at the Bayside Center in Ocean City), John has had the opportunity to sell



*Painting by John Miller*

some of his paintings at a benefit auction and display his work at several art shows, including one at the Renaissance Center. “Art has had a continuous and positive effect on John’s life,” explains PLAN/NJ service coordinator Francine Bates. “His work is beautiful and he is very proud of his accomplishments as an artist.”

John is also humble about his artistic talents. He explains that anyone can become an artist if they put their mind to it. Personally, he finds painting relaxing and loves to come home after a busy day and work on one of his ongoing projects, currently a circus scene. “Everyone has talent,” he explains. “You just have to find out what that talent is.” And John is one busy man. On weekends he can be found on the golf course with his roommate, playing the game that he loves. During the week John takes exercise classes, attends a day program in South Jersey, watches ball games, plays tennis and attends weekly art instruction. His art classes have offered him the opportunity to learn from



*John Miller*

renowned artists in the area. His work will be featured in Ocean City at a boardwalk art show this summer.

At home, John enjoys spending time with his roommate and keeping busy. John receives assistance for independent living from the staff of the Arc of Atlantic County. He is currently seeking

employment and has a good portfolio of job experiences, including working in a restaurant and performing maintenance duties for a floral distributor. “John is a people person at heart,” explains Bates. “He thrives when he has many personal connections and is far from shy.

Recently, when we were out to lunch, John asked to speak to the restaurant manager, introduced himself and requested an application for employment. His outgoing nature and personable demeanor are what make him so likeable and why he has so many friends.” Hopefully the restaurant will call. What they don’t know is that they would be hiring an accomplished artist as well.

# Informed Consent and Adults with Developmental Disabilities

By Herbert D. Hinkle, Esq.,  
and Ira M. Fingles, Esq.

**W**ith an ever-increasing focus on person-centered planning and service delivery, adults with developmental disabilities are expressing choices and making decisions about their own lives. This raises an important question about informed consent.

Obviously, some people with developmental disabilities are capable of making decisions for themselves. Many, however, are in need of a guardian.

Technically, adults under guardianship are not capable of giving legally valid informed consent — this is the job of the guardian. The existence of guardianship, however, does not mean that efforts should not be made to elicit meaningful input from the person with a disability, or that legal guardians are free to ignore such input.

Informed consent has a dimension beyond any requirements of law that is rooted in respect for the dignity of life and the inherent value of every human being. The discussion that follows embraces both legally and morally required informed consent.

One useful resource on the issue of informed consent is *A Guide to Consent*, published by the American Association on Intellectual and Developmental Disabilities (formerly the American Association on Mental Retardation). It explores legal implications of consent in critical life events such as adult guardianship, sexual activity, and home ownership. The guide identifies three elements of consent:

- (1) Capacity
- (2) Information and
- (3) Voluntariness.

The absence of any one of these elements will make the consent ineffective.

Capacity can take several forms. A person might lack the capacity because of legal status. For example, a minor or adult under guardianship cannot give legal consent. A 12-year-old child, no matter how precocious, lacks the capacity to give valid consent. Putting this aside, capacity can also refer to the mental capacity to comprehend the question at hand. An adult with significant intellectual disabilities cannot give valid consent even when no guardian has been appointed.



In my legal practice, I recall seeing a note in a file saying that a young man with disabilities, “C.S.,” would sign his mark on a piece of paper indicating that he wanted to remain in confinement, but before signing, he had to be given a cookie. C.S. could neither read nor understand the circumstances of his confinement. His mark on a document did not constitute consent.

The second element of consent is information. This in turn has several components. One is the information itself. The adult with disabilities must receive information that outlines the nature of the procedure or issue in question, and the possible consequences, both good and bad. Another component concerns how the information is delivered. It must be provided in a manner that can be understood by the person. While a written statement with the opportunity to answer questions might be sufficient in some cases, this would not suffice if the person cannot read or talk. The person with a developmental disability might have the capacity to understand, but only if the information is presented to him or her in a unique way, or perhaps repeated over several sessions.

The last element is voluntariness. Consent must be given willingly and free of coercion. Forced consent is obviously invalid, but the problems

of obtaining voluntary consent run deeper than this. One must ask, “Is the person with a developmental disability giving consent because:

- He or she is in custody and fearful of alienating the person seeking consent?
- He or she wants to please someone else?
- He or she wants to do what peers do?
- He or she lacks experience making decisions of this nature?
- He or she is unable to obtain independent advice?

The closer one examines the question of consent, the more complex it appears.

*A Guide to Consent* offers some useful advice. The procedures used to elicit consent should vary with the risk of harm associated with the decision. For example, the methods used to obtain consent for travel to a local basketball game and those used to obtain consent to open-heart surgery should not be the same. Similarly, the question of who should make the decision, and the extent to which input from the person with the disability will control, should vary as well. For instance, clients of mine allowed their daughter to choose the location of the apartment in which she would live, but first they made sure that the sponsoring agencies could provide the required level of supervision.

For more information or to order *A Guide to Consent*, go to <http://www.aamr.org/>.

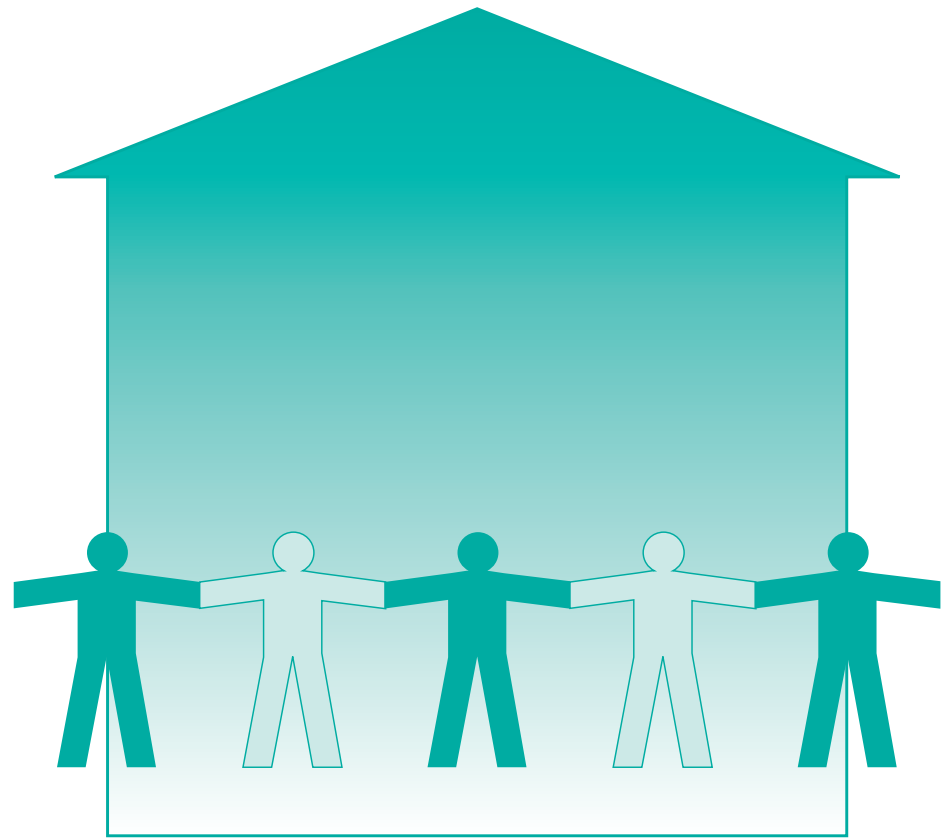
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*Attorneys at Hinkle, Fingles & Prior have more than 70 years of combined experience providing expert counsel and legal services to families of people with disabilities and seniors. The firm's attorneys have argued many of the precedent-setting cases affecting people with disabilities in New Jersey and Pennsylvania. For more information, please visit [www.hinkle1.com](http://www.hinkle1.com) or call (609) 896-4200.*

## *A Home of Their Own: Five Friends, LLC — A Success Story*

**W**hen Nancy Delaney's son Bob graduated from The Midland School 24 years ago, she went home, crawled into her bed, pulled the covers over her head and cried. The wonderful services that Bob had received throughout his school-age years had ended. "We were about to enter the uncertain world of 'adult services,' explains Nancy. Now 45, Bob had attended several schools and programs for children with autism before finding a "home" at The Midland School when he was eight years old. Nancy and her husband knew that they had their work cut out for them. They needed to secure a challenging day or work program and were thinking about Bob's future as an adult. As the parents of seven children (Bob was number five), they knew that Bob's siblings as adults would likely marry and have families of their own. But what about Bob's future? "We wanted to make sure he would have a full life with friends and supportive people surrounding him."

After graduation, Bob began working at Employment Horizons in Cedar Knolls and excelled at many jobs from assembly to document scanning. He also participated in the Morris County Adaptive Recreation Program (MCARP) and attended dances, took field trips, camped and participated in Special Olympics events. There weren't any community-based housing options available at the time for Bob, so the Delaneys got creative. Bob was enrolled in a state-sponsored program called Self-Determination (now Real Life Choices). Through Self-Determination, families were challenged to find innovative ways to support and enrich their children's lives. Bob already had recreation and work opportunities, but he did not have a home of his own. Nancy knew many of the families participating in the MCARP program, and she suggested to four of the families that they pool together their Self-Determination



resources and open their own home. "I went to Trenton and met with the head of Human Services at the time and convinced him that this was a viable option that would enrich the lives of five adults with disabilities," she says. "It was approved and we came up with the name Five Friends, LLC, and purchased a home in a residential neighborhood in Whippany. That was 12 years ago."

Five Friends, LLC, is like any family home. Three women and two men with varying disabilities share friendship and camaraderie like any family. They eat together, watch tv, and enjoy each other's company. Each roommate has his or her own room, with the men on one floor of the house and the women on another. "We have wonderful staff and are very fortunate that the home has been such a success," says Nancy. "We have had the same house manager for ten years."

The roommates even have a counselor who meets with them weekly to work on interpersonal communication and skills to live together successfully as a family. The Delaneys know Bob is fortunate. "I recommend to the many families with younger children with disabilities that I meet to start thinking about their future now," explains Nancy. "Interaction with other parents is the key to developing the kind of future that you want for your child."

Nancy Delaney refers to her son Bob as a "pioneer." It's easy to see why. As a competitor in the World Special Olympics in Austria, Bob has many talents. In addition to his athletic ability, he can assemble a complicated erector set in under two hours. The "pioneer" apple does not fall far from the Delaney tree, considering what Bob's parents have accomplished for their son.



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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.

## **JOIN US! "How to Be an Effective Guardian"**

**When:** Monday, June 28, 8:30-11:30 AM

**Where:** Boardroom, Atlantic Health System, 475 South Street, Morristown

Join Hunterdon County Surrogate Susan Hoffman and PLAN/NJ Executive Director Ellen Nalven as they discuss how to be an effective guardian. Topics will include the psychosocial aspects of guardianship (advocacy, medical attention, safety, social/emotional concerns of the ward and guardian, housing issues, client self-determination and client resistance to assistance) and completing the required annual report. Sponsored by the Guardianship Association of New Jersey.

## **On the Web**

The National Alliance on Mental Illness (NAMI) has partnered with non-profit organization [bringchange2mind.org](http://bringchange2mind.org) to develop an inspiring public service announcement about mental illness. Actress Glenn Close, whose sister has bipolar disorder, and actor/director Ron Howard created the public service announcement to raise awareness and reduce the stigma associated with mental illness. Their inspiring videos can be found at [www.bringchange2mind.org](http://www.bringchange2mind.org).

## ***A Time to Give***

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The professionals included in this resource list have indicated interest and experience in estate planning when individuals with disabilities are involved. The attorneys are grouped by:

1. those specializing in elder care, guardianship, special needs trusts, public benefits, special education laws; and
2. those specializing in personal injury and other legal support. Financial Advisors with experience in planning for the future of individuals with disabilities are also included.

Inclusion on this list does not represent a recommendation or endorsement by PLAN/NJ, and the list is not inclusive of all attorneys in New Jersey who provide such legal services. The following professionals contribute to PLAN/NJ, whether through financial support or in-kind contributions. Families should contact attorneys personally regarding services, fees, and to determine whether a particular attorney meets their family's needs.

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