



PLAN|NJ NEWS

THE NEWSLETTER OF PLANNED LIFETIME ASSISTANCE NETWORK OF NEW JERSEY
FUNDED BY THE NEW JERSEY STATE BAR FOUNDATION

SPRING 2014

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**Who will care for your loved
one when you are gone?**

PLAN NOW!

PLAN/NJ CELEBRATES 25 YEARS OF SERVICE IN NEW JERSEY

Planned Lifetime Assistance Network of New Jersey (PLAN/NJ) is excited to announce that 2014 marks our 25th anniversary of service to individuals with developmental disabilities and mental health challenges who reside in the state of New Jersey!

To commemorate our anniversary, PLAN/NJ will be hosting a 25th Anniversary Celebration on Thursday, June 5, 2014, at 6 pm at the New Jersey Law Center, located at One Constitution Square in New Brunswick. The festivities will include cocktails, hors d'oeuvres, a special celebrity silent fundraising auction and a keynote address by speaker Sarah Helena Vazquez.

As part of the evening's festivities, PLAN/NJ will also be honoring several distinguished individuals who have made significant and long-term contributions in improving outcomes and enhancing the quality of life to persons with developmental disabilities or mental health challenges in New Jersey. Awardees include:

Humanitarian Award

SYLVIA AXELROD

Executive Director, National Alliance on Mental Illness (NAMI) New Jersey

Legal Champion

TOM BEGLEY JR. ESQ., CELA

Begley Law Group, Legal Specialist for the Elderly and Disabled

Social Service Champions

HOPE AUTISM FOUNDATION

Danielle Guyet Lumby, Grace Ann Murphy, Denise Reiser — Founding Trustees of The Hope Autism Foundation

Parent Advocate

TASHA HALL JONES

Board Member, National Disability Rights Network

Leadership Award

SHAWN McINERNEY

Assistant Division Director, Division of Developmental Disabilities



Social Service Champion

BEVERLY ROBERTS

Director, Mainstreaming Medical Care Program, The ARC of New Jersey

PLAN/NJ was originally formed as the “ARC of New Jersey Community Trust Project” in 1987 when it was chartered to help parents and caregivers plan for the future care of a loved one with a disability. In 1988, PLAN/NJ became incorporated as an independent organization thanks to the help of Elizabeth Monroe Boggs, Ph.D., parent and internationally renowned policy maker, who was New Jersey's foremost scholar and advocate for people with developmental disabilities.

For more information on the event or to purchase tickets, please call Lynn Martorano, Development Director, at PLAN/NJ at (609) 254-7043 or lynn.martorano@plannj.org.

Suzanne Muldowney . . . *Joining the Parade*

With the arrival of warm weather come the many town parades that are held across New Jersey celebrating holidays and festivals. No one knows this better than Suzanne Muldowney, because she **LOVES** a parade. For years, she has been personally designing as well as sewing all her own “theme” costumes and participating in several parades that are held throughout the state each year. A metaphor for her life as well as the lives of so many other people with developmental disabilities or mental health challenges, Suzanne prefers to “participate” in the parade rather than watch it go by.

Suzanne has a “doer” philosophy. Going to school, living in her own condominium and using her creative flair to engage in her hobbies, throughout her life, Suzanne’s parents and brother always encouraged and assisted her with whatever she wished to participate in.

Several years ago, Suzanne’s parents contacted PLAN/NJ to learn about Life Planning and Home Visit Monitoring services. Concerned with the fact that they were both growing older and that Suzanne’s brother had moved out of state, they wanted to make sure Suzanne could continue to live actively and participate in the community even if they were not around anymore. The Muldowneys learned that PLAN/NJ’s client goals aim for each individual to have the ability to make choices and to continue to live a good life. PLAN/NJ Home Visit Monitoring Services would also always ensure a safe and appropriate home for Suzanne, as well as financial security. She would always have opportunities such as education and rewarding employment, should she desire. Suzanne would forever be protected from abuse and neglect, and she would continue to receive the same



kind of loving care that the Muldowneys provided her. They knew PLAN/NJ’s continuing Case Management Assistance would be essential to Suzanne’s long-term health and well-being.

With the assistance of PLAN/NJ, the Muldowneys created a LifePLAN for Suzanne, documenting her needs, wants, wishes, as well as her interests, activities and what makes her happy. The PLAN/NJ Service Coordinator documented in detail all the things Suzanne does to participate in the community and enjoy her life. They made provisions for Suzanne to continue to live in her own condominium and that food shopping, medical

appointments and hobbies would continue. They also made sure that Suzanne would have an emergency contact to call for help, should she ever have the need. Monthly Home Visiting Monitoring meetings were initiated and Suzanne continued to participate in “life.”

A few years later, Suzanne’s mother became ill and passed away. Her father passed away a short time after that.

Today, Suzanne’s brother, who continues to live out of state, is still an active participant in her life, and her PLAN/NJ Service Coordinator, Nadine, makes sure that Suzanne is continuing to enjoy her life, performing tasks for Suzanne that her family had previously helped her with.

Suzanne’s story is a wonderful example of the importance of Life Planning. Thanks to the creation of a LifePLAN and the installation of Home Visit Monitoring services, Suzanne’s life will continue to develop and grow, even if her family is not around to assist.

Suzanne is an active person in her community, and through these experiences she bonds with people, makes friends and

shares in experiences — many of the things that make life enjoyable. Thanks to her LifePLAN and Home Visiting Monitoring Services, PLAN/NJ ensures that this will continue for as long as Suzanne desires.

Throughout our lives, we can choose to “do” or we can “watch” other people do things. We can all pick and choose which parades to participate in, but if all we ever do is watch, life will march right by us. Perhaps we can all learn a thing or two from Suzanne Muldowney — that life is meant to be lived, not observed. So get out there and join the parade!

GUARDIANSHIP: A “New” Perspective

By Nina Weiss, Esq., and Anthony Serra, Esq., of the SerraWeiss Guardianship Law Center

By its very nature, guardianship is an involuntary process in which a person is declared to be an incapacitated person by a court and a surrogate decision maker (a guardian) is appointed to act on the person’s behalf. It is an arrangement that is imposed on a person as opposed to a consensual arrangement. A court makes a finding of incapacity based on the medical testimony of at least two physicians (or one physician and one psychologist) who are able to diagnose the underlying medical condition causing the diminished capacity and who can state that, in their medical opinion, the person is unfit and unable to manage his or her own affairs. These medical proofs, in conjunction with a showing of why a guardianship is necessary, form the basis for the court’s decision as to whether or not to impose a guardianship.

Rooted in the *parens patriae* jurisdiction of our courts (protection of those who cannot protect themselves), the fundamental purpose of guardianship is to provide assistance to those in need. At the same time, however, regardless of how well intentioned the process may be, the key is to strike the proper balance between providing assistance on one hand and minimizing the abridgment of one’s right of autonomy and self-governance. Philosophically, a guardianship should be a force of empowerment rather than a tool of suppression. U.S. Supreme Court Justice Brandeis articulated the need for balance in this area when he warned against the dangers of an overly paternalistic approach: “Experience should teach us to be most on our guard to protect liberty when Government’s purposes are beneficent. . . . The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding.” (*Olmstead v. United States*, 277 U.S. 438, 479, 1928, Justice Brandeis dissenting). We should all be “on guard” to protect our liberties, especially at times when others profess to be acting in our best interest.

A guardianship can represent a significant deprivation of civil rights and liberties and as such is viewed in the law as a remedy of last resort. It is always better to at least consider other, less-restrictive approaches to accommodating a person with diminished capacity, which is why

planning is so essential and critical. Proper advanced planning, while it cannot eliminate completely the need for a guardianship at some point in the future, can minimize significantly the likelihood that such a drastic measure will ever be necessary in the life of a person who develops diminished mental capacity. Simply stated, guardianship is not appropriate when there are other, less-restrictive ways of accommodating and meeting the needs of a person with diminished mental capacity. Other less-restrictive approaches to surrogate decision-making include the use of a Durable Power of Attorney, Advance Directive for Health Care (Living Will), a trust arrangement, joint ownership of assets, Conservatorship and even Limited Guardianship.

needs only a limited amount of assistance is saddled with a full, plenary guardian are miscarriages of justice that should not be tolerated. This leads to the ultimate question of delicately balancing the right to individual autonomy versus ensuring the best interests of individuals living in our society. To what extent should a person be able to live as he or she chooses? Do we have the absolute and unbridled right to live as we choose without interference by the government, even those governmental bodies created ostensibly to protect us from our own neglect and exploitation?

These are very difficult, though quite important questions, especially when dealing with the elderly who live in the community or those living with untreated mental illness. It’s true that we live in a



When dealing with a person with diminished mental capacity, whether it be an elderly individual who has lost capacity or a young adult living with a developmental disability who has always experienced diminished capacity in some regard, all reasonable attempts should be made to accommodate that person in the least restrictive manner possible under the circumstances. Such an approach, when applied honestly and in good faith, is intended to ensure a proper balance between protection of the individual on the one hand and respect for the person’s right of autonomy and self-determination on the other. Lopsided results in which a person with diminished capacity who

society that values highly our individual rights and freedom to choose; however, we also recognize that there are limits to what we have the “freedom” to do. For instance, we have the right to speak our mind about a particular cause or event, but we are not free to shout “fire” in a crowded movie theatre. The former is a form of speech protected by our Constitution, while the latter is conduct for which the speaker may very be in legal jeopardy. Similarly, a people are free to live in and maintain their own homes as they wish, though only to the extent their actions are not creating a public health hazard. A leaking fuel oil tank, for

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GUARDIANSHIP: A “New” Perspective

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instance, must be abated as soon as it is detected.

The more difficult dilemma, however, arises when a person who, from a purely objective standpoint, is living in deplorable conditions (ostensibly a chosen lifestyle), which may not be in their best interest. Such a scenario raises some compelling questions: Is their living condition truly an expression of their free will and choice, or is the condition a manifestation of an incapacity? When and under what circumstances should society protect us from our own actions and self-neglect?

These are indeed compelling questions that bring together the sometimes competing values of personal autonomy on the one hand versus a compassionate society that endeavors to protect those who are unable to protect themselves under the state’s *parens patriae* authority. And while few of us would argue over the merits of these two principles in the abstract, the true debate lies in where to strike the balance between the two and under what circumstances.

When faced with such a situation, it is essential to keep in mind at least two considerations. First, we must be very vigilant in keeping our own personal values and judgments out of the equation. That is to say, just because we would not choose to live a certain way does not mean someone else might consider it acceptable. This is not always easy and it requires us to not only be accepting of different ways of living, but we must also be tolerant of the potential risks posed by a lifestyle that may seem unhealthy and hazardous (indeed, even repulsive). Secondly, and perhaps most significant, is the presumption that we are all competent unless and until proven otherwise. Therefore, if we are going to impose a lifestyle change upon another because we feel this to be in that person’s best interest, there must be clear and convincing medical evidence within a reasonable degree of medical probability that the person suffers from a condition that is causing an incapacity, i.e., an inability to make informed choices. Simply looking at a lifestyle and concluding from that situation alone that there must be an incapacity is inappropriate and contrary to the law. The underlying medical condition that is causing the incapacity must be found independent of the objective manifestations of the person’s conduct and actions.

Only then can you properly conclude that what is being witnessed in terms of a lifestyle or home environment is in fact an outgrowth of an incapacity to which society ought to respond and ameliorate in the least restrictive way possible. Indeed, only then are the rights and freedoms of the person truly protected and preserved.

Despite the push in New Jersey toward limited guardianships and for least-restrictive arrangements, practitioners are frequently not held accountable for implementation of these less-restrictive approaches. For example, courts currently do not require the petitioner of a guardianship to set forth any attempts made at a less-restrictive alternative to the guardianship. Have home services been attempted? What about a bill payer? Will the alleged incapacitated person consent to have a conservator appointed for money issues? Yet a guardianship is the most restrictive protective arrangement in a broad spectrum of options. So the truth is, in many circumstances, “least-restrictive arrangement” is merely rhetoric and not reality. This brings us to the critical role of counsel in guardianship proceedings.

Although a guardianship, by its nature, is paternalistic and most often brought for the well-being of the individual, because it involves the taking away of rights from one individual and vesting them in another, the person alleged to be incapacitated is entitled to certain basic due process protections, one of them being the appointment of counsel (it should be noted that the individual can also privately retain counsel of his or her choice). Those petitioning for guardianship on behalf of a loved one should be careful not to confuse the role of counsel with the role of the guardian (surrogate decision maker) or a guardian *ad litem* (person asked by the court to give an opinion as to what is in the person’s best interest). The New Jersey Supreme Court in the Matter of MR also clarified the role of court-appointed counsel as a zealous advocate for the stated wishes of the client. “. . . [t]he role of an attorney for a developmentally disabled person is like that of an attorney representing any other client. Advocacy that is diluted by excessive concern for the client’s best interests would raise troubling questions for attorneys in an adversarial system.” Although it may be difficult, families should respect the attorney’s role as an advocate for the stated wishes of the individual, even if the family believes the

stated wishes of the person may be unrealistic or unreasonable. It is a critical part of the process, and if the attorney performs his or her role pursuant to the dictates of the law, a just, meaningful and appropriate result will most likely be the outcome of the guardianship. The Court in MR further articulated that even if it is ultimately determined that the individual requires the appointment of a guardian for decision-making, that does not necessarily mean that the person has a complete inability to make and participate in certain decisions. In the words of the Supreme Court: “The primary duty of the attorney for such a person is to protect that person’s rights, including the right to make decisions on specific matters.” (In M.R.’s case, it was the question of where MR wanted to live).

The law and standards surrounding guardianship clearly recognize the delicate balance between protection and self-determination.

Due to guardianship being adjudicated in the context of an adversarial system, at times the attorney for the alleged incapacitated person becomes adverse to the petitioners; oftentimes the petitioners lack understanding about the proper role of counsel and take offense to anyone questioning the guardianship application. Attorneys for those petitioning for guardianship should at the outset educate their clients regarding the process, including the role of counsel, and give them an appreciation of the civil rights aspects of the matter. Further, courts should demand that attorneys proceed in accordance with these fundamental principles and should balk upon receipt of recommendations based upon principles of best interests.

It is critical to note that even if a plenary guardian is ultimately appointed for an individual, the guardian nonetheless must adhere to the value system of the ward and exercise decision-making in the least-restrictive manner. The National Guardianship Association sets forth standards for decision-making in this regard (Standard 7). Specifically, a guardian shall identify and advocate for

the person's goals, needs, and preferences. Goals are what are important to the person under guardianship, whereas preferences are specific expressions of choice. Only when the person, even with assistance, cannot express his or her goals and preferences, shall the guardian seek input from others familiar with the person to determine what the individual would have wanted. And only when the person's goals and preferences cannot be ascertained may the guardian make a decision in the person's best interest.

Substituted Judgment is the principle of decision-making that substitutes the decision the person would have made when the person had capacity as the guiding force in any surrogate decision the guardian makes. Substituted Judgment promotes the underlying values of self-determination and well-being of the person. On the other hand, Best Interest is the principle of decision-making that should be used only when the person has never had capacity, when the person's goals and preferences cannot be ascertained even with support, or when following the person's wishes would cause substantial harm to the person. The Best Interest principle requires the guardian to consider past practice and evaluate reliable evidence of likely choices.

The NGA further sets forth standards for guardians regarding Least-Restrictive Alternatives (Standard 8). The guardian shall carefully evaluate the alternatives that are available and choose the one that best meets the personal and financial goals, needs, and preferences of the person under guardianship while placing the least restrictions on his or her freedom, rights, and ability to control his or her environment. The guardian shall weigh the risks and benefits and develop a balance between maximizing the independence and self-determination of the person and maintaining the person's dignity, protection, and safety. Courts should ensure when guardians are appointed that they are familiar with these fundamental principles.

The law and standards surrounding guardianship clearly recognize the delicate balance between protection and self-determination and give practitioners and families guidelines in order to strike the proper balance. It is up to all of us to adhere to these principles in an effort to ensure just, reasonable, and least-restrictive results. These indeed are not new concepts; however, heretofore, there has not been strict adherence to these principles, perhaps making this a new perspective on guardianship.

PLAN/NJ Welcomes New Board Member SAMANTHA J. HERRICK



PLAN/NJ is pleased to announce Samantha J. Herrick, PhD, CRC, NCC, has joined our Board of Directors. An Assistant Professor with the Rutgers School of Health-Related Professions, Dr. Herrick has worked as a counselor and human services professional in both community and higher education settings for over 15 years.

She began her career in vocational rehabilitation for people with significant disabilities with community agencies in the Berkshires of Massachusetts. She later worked in disability support services at The State University of New York at New Paltz and The Pennsylvania State University.

She is a graduate of the counselor education and supervision doctoral program at The Pennsylvania State University, where a researcher/practitioner/educator model is espoused. She obtained her master's degree in rehabilitation counseling and disability studies from Springfield College and her bachelor of arts degree in communications as a scholarship athlete from The University of Rhode Island.

A Certified Rehabilitation Counselor since 2005 and a National Certified Counselor since 2008, Dr. Herrick has presented at both national and regional professional conferences on topics such as universal design for instruction, counseling people with autism spectrum disorder, small group interventions for college students with autism spectrum disorder, and promoting disability support services as a professional option for rehabilitation counselors. Her research interests include adaptation to college for students with disabilities, barriers to higher education for students with disabilities, developmental disabilities, and especially autism spectrum disorders.

Dr. Herrick was named chair of the department CORE/CACREP accreditation subcommittee, was nominated for the 2013 School of Health-Related Professions Excellence in Teaching Award, and was awarded a 2013 Emerging Leaders Fellowship by the Association for Counselor Education and Supervision.

PLAN/NJ PROFESSIONAL SPONSORS DIRECTORY

Attorneys and Financial Advisors/Planners

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 focusing on elder care, guardianship, special needs trusts, public benefits, special education laws; and 2. those focused on 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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