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Ellie Byra joins the PLAN/NJ Board

PLAN/NJ is pleased to announce that Ellie Byra, a devoted advocate for individuals with disabilities and their families, and for the philosophy of inclusion, has joined the PLAN/NJ Board of Directors.

“Supporting individuals and families with disabilities has always been a primary concern for me,” said Ellie. “I have been an advocate for Special Education and Developmental Disability since my son Matthew was born. And my sister Karen had a developmental

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Sharing Hope and Happiness

We love getting emails from our adult clients. Patrick recently wrote with the exciting details of preparing for a trip to Florida. Despite living with developmental disabilities, he leads an independent life, in part because of the Guardianship services he receives from PLAN/NJ. Patrick enjoys a meaningful relationship with the Director of Social Services and with the staff at his supportive living home.

CLIENT VOICES

Good Morning, Mr. Jason Miller, of the company which of course is called PLAN/NJ,

I have some very important, but really exciting, and also very interesting news that I am going to tell you. I am ready to go on this Walt Disney World Resort Summer Dream Vacation, and I am positively and definitely sure that this trip is for real.

This most amazing, adorable, incredible, very useful, very helpful, very little, very lovely, ever so enchanted, most wonderful, ever so beloved, handsome, young, bright, very interesting, and most serious,

but also, ever so very important and beautiful young gentleman, has done everything that my apartment staff assistants and managers have let me do.

My apartment staff assistant took me to the barbershop, and I have gotten myself a new & improved haircut. I also went to that hospital to get my blood work checked. I have to tell you now that I am still afraid of those needles, but not this time. I was fine at the end of the appointment.

So I am now just about set and ready to do some traveling. I will be leaving with 1 or 2 staff assistants, and I certainly do want to go with my counselor; I always want for him to join in on the fun, joy, excitement, glamour, surprises, and all of the other things in history, in hope, and in happiness.

When I do get over there to the Walt Disney World Resort area, it will be very hazy, hot, and humid. I will have to put a lot of suntan lotion and sunscreen on me. Not only that, it would be a good thing to take my umbrella with me,

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Ellie Byra Joins the Board (continued from page 1)

disability and lived in a group home.”

Ellie’s advocacy and volunteer work began as when she became President of the Parent Association of the Warren County Day Training Center, where her son attended programs. There she became interested in working to open up options for children’s day training, which led to other opportunities to be of service, including with the Arc of New Jersey. Over the years, the Arc has played a major role in Ellie’s life on both a local and statewide level; she has held various positions for the Arc of Warren County, the Arc of Hunterdon County, and the Arc of New Jersey.

She received her Bachelor of Arts in Special Education from the University of Massachusetts at Lowell, and her Master of Arts in Special Education from Southern Connecticut State College, after which she taught Special Education and first grade.

Ellie served for nine years as a member of Disability Rights New Jersey’s (DRNJ) Board of Directors. Currently, she is a member of DRNJ’s Protection and Advocacy for Developmental Disabilities Advisory Committee and is a current member of the New Jersey Council on Disabilities (NJCDD), where she previously served on its board and as the Chairperson of its Policy Committee.

Ellie also serves on Hunterdon County’s Planning and Transition team, on the Council on Developmental Disabilities Education Committee, as Chairperson and member

of New Jersey’s Special Education Advisory Council, and as a member of Rush Holt’s Education committee.

“We are thrilled to have Ellie serve on our Executive Board,” said Ellen Nalven, Executive Director. “Her many years of experience and devotion, and her wealth of knowledge will be an asset to our organization.”

Ellie has received several distinguished honors, including Volunteer of the Year from both the Arc of Warren County and the Arc of New Jersey, the Diana Cuthbertson Award, the State Special Education Advisory Council Award, the One of the Heroes Award from the Arc of New Jersey, the Council on Family Support Award, and the Elizabeth Boggs Family Member Advocate Award.

“Perhaps my greatest joy comes in looking back and realizing how far we have come. When my sister was born 49 years ago, communities offered absolutely no educational or family supports as compared to the caring environments that are in place today,” said Ellie. “I also recognize the long road ahead.”



Keeping You Current: Legislative Developments Impacting Individuals with Disabilities

by Richard I. Miller, Esq.

Recent legislative efforts at the national level have focused on the promotion of self-determination for individuals with disabilities. The 21st Century Cures Act of 2016, the Special Trust Fairness Act of 2015, and the Achieving a Better Life Experience (ABLE) Act of 2014 are examples of this trend.

Many government programs have a resource limit of \$2,000 that results in individuals having to spend down nearly all of their assets in order to be eligible for benefits. Special Needs Trusts (SNTs) provide an opportunity to preserve the assets of individuals with disabilities while allowing them to qualify for government benefits such as Medicaid, SSI, and services from the Division of Developmental Disabilities (DDD).

SNTs permit individuals to maintain assets to pay for expenses not covered by government programs – thereby enhancing the beneficiary's quality of life. For example, the money in an SNT can be used to pay for the beneficiary's furnishings, electronics, travel, and entertainment.

Until recently, an SNT could only be established by the beneficiary's parent or grandparent, a legal guardian, or a court. Individuals with disabilities could not set up an SNT for themselves. As a result, it was often necessary to obtain court approval to establish an SNT, thereby creating unnecessary legal costs.

This inequity was rectified on December 13, 2016 when President Obama signed the 21st Century Cures Act which incorporates the Special Needs Trust Fairness Act of 2015. This act enables individuals with disabilities who have the capacity to create their own SNT. As a result, individuals with disabilities and capacity no longer require someone else to establish an SNT on their behalf. The Act applies to trusts established on or after December 13, 2016.

The ABLE Act, signed into law on December 19, 2014, allows

for the establishment of a tax advantaged savings account for individuals with disabilities (similar to a 529 account). Like an SNT, the funds in an ABLE account are not treated as a resource for Medicaid, SSI or DDD. Individuals with disabilities are permitted to establish and control their own ABLE account. This provides an advantage over SNT's which cannot be controlled by the individual with disabilities.

ABLE accounts do, however, have certain restrictions that limit their use and benefit. By way of illustration, an individual must be disabled prior to turning age 26; the total annual contribution cannot exceed \$14,000; and accounts in excess of

\$100,000 will cause disqualification from SSI. The account must be established in the State where the eligible individual resides or a State that specifically accepts non-resident accounts, such as Ohio, Nebraska and Tennessee.

SNTs and ABLE accounts both have payback requirements to reimburse Medicaid for medical expenses paid on behalf of the beneficiary. In contrast, Third-Party Supplemental Needs Trusts (i.e. trusts funded with assets of someone other than the beneficiary) do not have payback obligations.

Advocates will continue to advance new laws which further protect individuals with disabilities and that ensure self-determination.

Due to the intricacies and differences between SNTs and ABLE accounts, it is important to seek the appropriate legal and tax advice to learn which option is right for you and your family.

“Recent legislative efforts at the national level have focused on promoting self-determination for individuals with disabilities.”

Richard I. Miller, Esq. is designated as a “Certified Elder Law Attorney” by the National Elder Law Foundation and practices law at Mandelbaum Salsburg located in Roseland, NJ.

Sharing Hope and Happiness (continued from page 1)

because it always keeps me dry. I will have to make sure that the lines don't look too bad, and they will never be too long to stand in.

After I send this email on my new & improved iPad, I hope you will be kind enough to send me a reply, and you will use your iPhone to do it. I have two very important United Airlines Economy Class flights from Newark Liberty International Airport to Orlando

International Airport and back home that I want you to book for me.

Once again, Mr. Jason Miller of PLAN/NJ, thank you ever so very much for letting me tell you about it, and I will keep up this behavior, and keep on acting perfectly, and properly just like a gentleman, and a very important human being.

Thank you for letting me write this email to you, and I will indeed have

the honor and the best opportunity to wish you a very smooth, and very safe, and pleasant day, and now I will press the “Send” button to send it over to you.

Sincerely,
Patrick

This email was slightly edited, and the client's name and some facts were altered to maintain privacy.



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