



HELPING HAND

An Update from the Special Needs Practice Group

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SPECIAL NEEDS & ELDER LAW PRACTICE GROUPS

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Practice Group Leader

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Marisa W. Higgins, Esq.
Mia H. Lahti, Esq.
Michael T. Lahti, Esq.
John J. McNicholas, Esq.
Lauren E. Miller, Esq.
Mary F. Proulx, Esq.
Dani N. Ruran, Esq.
Theresa M. Varnet, Esq.
Collin A. Weiss, Esq.

TRUST SERVICES

Toni Brogna
Director of Trust Services
Jennifer Zaparaskas
Paralegal

ADMINISTRATIVE SUPPORT STAFF

Wilma Vallejos
Manager, Special Needs Practice Group
Lainie Petrou
Paralegal
Danielle Porter
Administrative Assistant

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PRACTICE GROUP MESSAGE

By Frederick M. Misilo, Jr., Esq.



I was honored and privileged to have been elected as the President of The Arc of the United States, Inc., at its annual business meeting in November. My first job, over 40 years ago, was with a local Arc chapter,

where I was first introduced to this impressive organization. At present, it is the largest community-based civil rights organization dedicated to improving the lives of individuals with intellectual and developmental disabilities and their families in the nation. It has over 650 chapters, over 100,000 employees and serves over 1,000,000 individuals across the country. I've included an excerpt of my incoming remarks in this newsletter.

It is my pleasure to introduce two guest writers in this edition of Helping Hand. In my work with a diverse set of clients, an essential element to success is fostering partnerships with people and organizations able to offer services and supports useful to our clients. These two articles exemplify the importance of connecting our clients with quality services and resources that can be useful in meeting the services and support needs of their family member with differing abilities.

In his article, Jay O'Brien of the Asperger's Association of New England (AANE) describes a new, innovative service, LifeNet, offered to individuals and their families. LifeNet is intended to provide gap-filling services to individuals in a range of practical and important ways. LifeNet will

offer, for example, help with, among other things, budgeting, arranging and managing health and dental appointments, bill paying, and transportation. Through a team-based approach, LifeNet offers a comprehensive, holistic approach to supporting individuals in promoting an independent and enjoyable life. At this time, AANE is offering LifeNet services on a private-pay basis only.

Rebecca Moore certainly exemplifies the adage of "making lemonade out of lemons." In March 2015, Rebecca sustained a serious fractured ankle in a bad bike accident. This experience opened her eyes to the challenges faced daily by individuals with disabilities. As a result, she resolved to make a difference by providing resources to persons with disabilities through launching AbleRise, a website designed to empower persons with disabilities as well as their families and friends. Her article contains refreshing practical advice and provides a glimpse of the resources available on the AbleRise website.

Attorney Lauren Miller's article highlights the interrelationship of beneficiary designations with estate planning documents. It is important that your assets are properly allocated to the appropriate estate planning documents by beneficiary designation or by ownership. Financial advisors, insurance professionals, estate planning lawyers and their mutual clients should work as a team to ensure that this issue is not overlooked. **FT**

To contact me on these or any other related issues, my direct line is 508-459-8059 and my email address is fmisilo@fletchertilton.com.

WHO WILL SUPPORT OUR ADULT CHILD ON THE SPECTRUM WHEN WE'RE GONE?

By guest contributor Jay W. O'Brien, MPA, of AANE



For many parents of adult children with an Asperger/autism diagnosis, this is a keep-you-up-at-night question, one with no easy answer. And it can prompt a seemingly endless number of corollary questions.

Who will be their "go-to" people when they get stuck, have a question, need a reminder or require

support in making good decisions? Who'll work with them to transition to and maintain a healthy, tidy and safe environment where they live? Help them pursue and sustain success at work? Follow through on doctors' orders and appointments? Help them manage their money, pay their bills and stick to a budget? Make sure they get or stay engaged in the community – based on their interests – and don't become isolated and withdrawn?

Continued on pg. 2

AANE is building the LifeNet case management team to be a central part of an adult's safety net and network that can support them and their parents as they move through adulthood.



No matter their intelligence and capabilities in certain areas of life, many adults on the spectrum struggle with some combination of the above. Yet until recently, they've been shut out of funding and services to help them live independently as adults. Why? Traditionally, funding for adults has been directed to those with intellectual and developmental disabilities who are deemed to have greater needs. Even for those adults considered "newly eligible" for services under the Massachusetts Autism Omnibus Bill passed in 2014, the funding appropriated by the state legislature has lagged behind, covering services for only a fraction of adults on the spectrum who now qualify.

AANE LAUNCHING NEW PROGRAM TO HELP FILL GAP IN ADULT SERVICES

In September, after seven months of intensive planning by AANE staff and leadership, the AANE Board of Directors unanimously voted to launch the new LifeNet independent living support program in January 2019. Initially, LifeNet (www.aane.org/LifeNet) will be offered as a private-pay case management service for adults with Asperger syndrome or similar autism spectrum profiles. The long-term goal is to tap into state agency funding, including from the Department of Developmental Services (DDS), to extend the program to all adults who qualify, regardless of income or assets.

AANE is building the LifeNet case management team to be a central part of an adult's safety net and network that can support them and their parents as they move through adulthood. For parents of adults, the LifeNet program addresses questions like "Who will support our adult child when we're gone?" or "Who can help our child live independently of us while we can still help with the transition?" For adults themselves, we'll address "How will I get the support I need to continue living independently as I grow older?"

LifeNet offers caring support for adults on the spectrum:

- Maintaining a healthy and safe living environment in their apartment or home
- Arranging and keeping health care and dental appointments, filling prescriptions, etc.
- Managing budgets, bills and money
- Tending to nutrition, food safety, exercise and hygiene

- Engaging socially – around their interests and at their pace
- Encouraging and supporting productive employment and/or volunteer opportunities
- Offering transportation and travel guidance and more

Overall, the LifeNet Team offers personal support and advocacy just like a parent would provide, such as:

- Regular phone/text check-ins and in-person visits
- Responsiveness to questions or issues as they arise
- Monitoring and responding to changes in well-being
- Assessing options, and supporting good decision-making
- Addressing unmet needs, and making progress toward personal goals
- Coordination between providers, trustees and others in the adult's support network
- Help completing forms/paperwork and meeting deadlines

LIFENET'S TEAM-BASED APPROACH

Much more than just a single caseworker, each adult's LifeNet Team consists of an array of people who have experience in understanding and meeting the needs of adults on the autism spectrum. The LifeNet Team serves as a "surrogate family" of professionals and volunteers who develop relationships with and care about the adults, offering them a greater sense of community and belonging. LifeNet Team members include:

1. **Personal Advocate** – experienced, degreed social work case manager
2. **Support Partner** – field-based support staff
3. **Licensed Clinical Supervisor** – licensed clinical social work supervisor
4. **LifeNet Program Director** – overall administrator and ombudsman
5. **Host Family** – volunteer local family that shares companionship with a LifeNet adult
6. **Peer/Friend** – a similar-age adult peer matched from within the AANE community

"LifeNet combines AANE's deep understanding of the needs of adults with an Asperger/autism profile with an experienced team that can support their independent living for, conceivably, the rest of their lives," said Jay O'Brien, AANE LifeNet's program director. "We believe LifeNet will have particular value as parents prepare for the day when they may no longer be in a position to serve as their adult child's sole or primary caregivers."

"The response we've received from families so far confirms why we're launching LifeNet," he added. "We've been told, 'If we were to write out what we're looking for, this would be it,' and 'This is exactly what we've been waiting for.'"

For details about LifeNet including fees and eligibility, visit www.aane.org/LifeNet, or contact Jay O'Brien at 617-393-3824 ext. 60 or jay.obrien@aane.org. **FT**

REMARKS OF FRED MISILO UPON HIS ELECTION AS PRESIDENT OF THE ARC OF THE UNITED STATES



November 8, 2018

The Arc has a rich history spanning over 60 years in which the organization has transformed the landscape of disability law, public policy, and services and supports. As the largest national community-based organization advocating for persons with intellectual and developmental disabilities, we have moved mountains.

What is it about our organization that has made it so unique and so important? I believe it is the people. Countless people on whose shoulders we currently stand, like Elizabeth Boggs, Gunnar Dybwad and so many others who gave so much time, leadership and passion to our effort. These are historical giants who have impacted generations of people in this field. We can also look to Rud Turnbull, who has throughout his life demonstrated a commitment to the core values of The Arc as a vibrant civil rights organization and who we will honor during this Convention.

It is also people like Barb Coppens who, as a self-advocate, is a fierce force to be reckoned with on issues of self-determination and basic civil and human rights. And James Meadours, a longtime and courageous self-advocate who has held leadership positions in a number of disability rights efforts.

Look around this room – to the people to your left and to your right. You are The Arc. Your work, your passion, your vision will sustain and propel this organization forward in its important work long after this Convention is over.

Each of us has our own personal reasons for our continued commitment to this organization. For me, it began when I, as a nineteen-year-old university student, worked at Belchertown State School, where I witnessed the dehumanization of people who were not treated with basic dignity, privacy and respect.

It continued when I was a community outreach worker working with families who chose, against the prevailing professional advice of that time, to not place their son or daughter in an institution. Instead, they chose to keep their family member at home with them. This is where I witnessed how families faced isolation in their own communities without the support of local school districts, faith communities and health care providers.

Over time, it was The Arc, not only in Massachusetts but across the nation, led by families and advocates who fought for changes in both institutional settings and community supports. These efforts resulted, for example, in the special education entitlement, closure of state institutions and the development of community-based services and supports.

However, as everyone in this room knows, we are far from having accomplished a sustainable future for persons with intellectual and developmental disabilities and their families in 2018. So, while we are a non partisan, nonprofit corporation, we are not and never can be a “go along to get along” organization with respect to important public policy affecting the interests of people with intellectual and developmental disabilities.

It is in the DNA of this organization to be a fierce opponent of bias, a courageous advocate for basic civil and human rights, and a strong force for community. We must continue to be a vigilant and vibrant voice for protecting fundamental decency with respect to our federal policy priorities.

So, what are these priorities? These priorities are, at their core, what all people want for themselves and their families – a good life.

For families, that means having reasonable access to family supports.

For individuals, it means:

- A home of one’s own choosing in their community.
- Meaningful work and community engagement and the support to attain these.
- Affordable and quality health care and health insurance without regard to pre-existing conditions and lifetime caps.
- Income maintenance benefits.
- Protection and expansion of long-term services and supports.
- Robust, individualized education services, including preparation for adulthood.

And for all of us:

- Fair federal fiscal policies that produce adequate tax revenue which provides the necessary investment in human capital and the infrastructure of services and supports for all persons who require them.
- Certainly, the greatest and wealthiest nation in the world has it within its capacity to ensure that all of its citizens, including persons with differing abilities, can enjoy the fullness of their potential.

To this end and more, our entire community–The Arc’s community–must commit itself to active citizen participation.

We must also reach out to other groups and organizations who share our core values and priorities to inform, educate and persuade not only our elected leaders but the general public. And this can’t be only a Facebook activism, but virtual and physical. Together, we can be the conscience of our country in this perilous time on these important issues.

As we begin our strategic planning effort, we cannot rely solely on the paradigms of the past to guide us into the future. We all know driving by looking in the rearview mirror is a sure recipe for disaster. We, as a community, are facing issues unique to this current time. For example, issues around self-directed services, supported decision-making, concepts of community and person-centered support plan development will challenge people, programs and systems. The development of these concepts requires new paradigms and solutions to truly meet people’s needs.

My friends, our community still contends with systemic and societal barriers grounded in bias, misunderstanding or indifference from the greater community. Let us commit today to shatter those barriers – and let us start with ourselves and then move outward. Let the sound be heard at all levels of our organization.

And tomorrow it will be commonplace that our friends, our family members, ourselves ... will walk onto ANY bus, into ANY school, ANY doctor's office, ANY place that serves the public, and know they will be treated with respect and dignity. I strongly believe that our work together has established a firm foundation for individuals and families. There is much to be proud of.

Throughout this Convention, we honor many people, businesses and groups who are truly examples of excellence and best practices. We celebrate these tremendous efforts. We are on the right course. However, I suspect that to fully reach our potential, we must face the future with a continued and increased willingness to embrace change and question conventional wisdom.

One absolute priority for our organization must be to ensure that we are a welcoming, inclusive and diverse community that is respectful of all. This will not happen without intentional effort, and we must rededicate ourselves to this priority at all levels of the organization.

We must reach out and involve historically unrepresented and underrepresented individuals and groups to ensure that our organization, at all levels, looks like all Americans.

And when we succeed, and succeed we will, in reaching that next level, we won't be helping just our family members, friends and ourselves. No, we will be building a better society for all its citizens – for everyone understands the need for acceptance; all worry about access in one form or another. In the final analysis, we will have created a more welcoming society for all.

Finally, I want to express my sincere thanks and appreciation for the opportunity to serve as President of this organization. I promise that I will do my very best to listen, respect opinions and be engaged in our work together over the next two years. Thank you for your continued work in all that we do. I look forward to working with all of you on our continued success. **FT**

THE IMPORTANCE OF INCORPORATING BENEFICIARY DESIGNATIONS INTO AN ESTATE PLAN

By Lauren E. Miller, Esq.



Beneficiary designations are a crucial—and often overlooked—part of estate planning. For parents who have children with special needs, updating your beneficiary designations is of particular importance. A beneficiary designation is a way for you to designate how an asset will be distributed upon your death. Two common types of assets that allow you to designate beneficiaries are life insurance and retirement accounts, such as an IRA or a 401(k).

Special needs planning necessarily includes one or more special needs trusts, and failure to update your beneficiary designations to reflect these trusts can have severe consequences, such as jeopardizing your child's eligibility for public benefits. When a child with special needs inherits assets outright while receiving means-tested public benefits, often the only way to reestablish benefit eligibility is by moving the assets to a first-party (OBRA '93) trust. This is carried out through a time-consuming and expensive court process known as a single transaction conservatorship. In addition, an OBRA '93 trust by definition includes a Medicaid payback provision, so after the death of the child, the state is reimbursed from the trust up to the amount of benefits paid during that child's lifetime. If there is anything left in the trust after Medicaid is reimbursed, only then will the contingent beneficiaries named in the trust be entitled to any distributions. Contrast this with a third-party special needs trust, which is created and funded by someone other than the beneficiary with special needs (such as through a beneficiary designation) and does not require a Medicaid payback clause.

You may have completed a beneficiary designation form at the time you purchased a life insurance policy or opened a retirement account. To ensure that your assets are distributed pursuant to your current wishes and in accordance with your current special needs plan, you should review your beneficiary designations every three to five years or when you experience any major life event.

For families of children with special needs, updating your beneficiary designations is just as important as executing special needs planning documents. Follow this checklist to assess the state of your current beneficiary designations.

SPECIAL NEEDS BENEFICIARY DESIGNATION CHECKLIST

- Identify your accounts that allow for or require beneficiary designations.
- If you do not already have copies of the current beneficiary designations for each account, contact the financial institution to obtain a copy.
- Review the beneficiary designations with your attorney to confirm that your child's special needs trust is named in the proper position; if you have more than one type of special needs trust (e.g., first-party trust vs. third-party trust), confirm with your attorney that the correct trust is listed on each beneficiary designation.
- Once you have updated all beneficiary designations, forward a copy to your attorney, and keep a copy with your other important paperwork. **FT**

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MAKE LIVING AT HOME WITH A DISABILITY EASIER: 3 THINGS YOU CAN DO

By Rebecca Moore

Learning to live with a disability can be a challenge, but it does not have to keep you from living your life to the fullest. If you are one of the millions of Americans living with differing abilities, you can make the most of your life, but it helps to start by making the most of your life at home. Here are some ways you can make your daily routine a little easier.

MAKE SURE YOUR HOME IS WORKING FOR YOU

Making your home more accessible should always be your first priority. Think about features that can help you live more independently, and then find a contractor to add them to your home. If you are living with limited mobility, you may want to consider remodels to boost accessibility. Simple changes, such as widening doorways and lowering countertops, can make it easier to move around your home and complete basic tasks like cooking and cleaning. You may want to work with contractors who are experienced with making accessibility upgrades and who can provide additional ideas on how to make your home more accessible. For projects where finances are an issue, consider looking into funding options (visit <https://www.handiramp.com/funding.htm>) that may be available to help you upgrade your home, such as VA loans or federal grants. Even if remodels are not necessary in your home, think about some DIY projects that can increase safety and simplicity, such as adding grab bars in the bathroom if you have mobility issues or using textured tape to label items around your home if you live with limited or no vision.

THINK ABOUT ADDING A DOG TO YOUR LIFE

One way to make your life a little easier (and happier as well) is to get a service dog. Service dogs go beyond just helping the blind. Aside from being loving companions, service dogs (visit <https://www.rover.com/blog/getting-a-service-dog/>) can offer help as well as emotional support for those with differing abilities. Depending on the disability, there may even be organizations and groups that

can help you find the perfect canine companion to help you with your everyday needs. From Dogs for the Deaf (visit <https://www.dogsforbetterlives.org/>) to America's VetDogs (visit <https://www.vetdogs.org/>), there are dogs trained to meet a variety of needs.

In addition to providing essential daily services, a service dog can offer other health benefits (visit <https://tinyurl.com/ycollnyl>). Having a dog can lower your blood pressure, reduce feelings of depression and even help relieve stress and anxiety. However, if your mobility is limited or you are older, dogs can lead to falls too, so take steps to reduce this hazard.

HIRE PEOPLE TO HELP WITH TASKS AT HOME

Keeping up with daily tasks can be tricky, especially if you have a busy career, growing children or any other responsibilities. However, a disability doesn't have to slow you down. Hiring people to help around the house (visit <https://tinyurl.com/yddev4mq>) can make life a little easier. Depending on your needs and budget, you can find part-time or full-time assistance with time-consuming tasks like prepping meals, shopping for food and cleaning up around your home. Hiring a housekeeper (visit <https://tinyurl.com/y7gmzncp>) can even make you feel happier. Research shows that people who spend money on time-saving services rather than material possessions tend to feel more content and happy in their everyday lives. By getting help with chores around your home, you can leave more time in your busy schedule for other tasks, such as practicing self-care or getting enough exercise.

In so many ways, living with a disability is a lot like living without one, but there are times when you may need a little help with certain things. Looking into simple measures that can make your life more manageable is a smart move for anyone. Whether it's modifying your home or getting help from pets and other people, finding ways to make your home life easier can help you feel happier every single day. **FT**

Aside from being loving companions, service dogs can offer help as well as emotional support for those with differing abilities.



Contributed by guest writer Rebecca Moore of AbleRise.

In March 2015, Rebecca Moore became temporarily disabled. She suddenly began to understand the daily difficulties, challenges, and lack of understanding faced by people with disabilities.

Rebecca teamed up with amateur web developer, Martin, to launch AbleRise, a site designed to empower people with disabilities as well as their friends and family with resources, community acceptance and assistance.

The Fletcher Tilton Special Needs Practice Group provides legal counseling, advocacy and innovative solutions on behalf of individuals with differing abilities and their families. We strive to serve as a reliable, trusted advisor committed to providing excellent service to our clients throughout their lifetime. We recognize the importance of treating our clients with respect and dignity.

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