

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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