

# The Meaningful Participator

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## Life Care Planning for Parents/Guardians of Special Needs Children (or Adult Children)

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### Notes from Nessa

Over the past few years, we have seen many changes regarding laws pertaining to education and children with special needs. In 2001, *No Child Left Behind* was enacted and in 2004, the *Individuals with Disabilities Education Act* (IDEA) was amended. In light of these legislative enactments and in efforts to align its Operating Standards with both acts, Ohio released a revised *Operating Standards for Ohio Educational Agencies Serving Children with Disabilities*, effective on July 1, 2008. The amended standards can be found on the Ohio Department of Education's website (<http://www.ode.state.oh.us>).

I encourage parents to review these new standards as a way to strengthen their advocacy efforts for their child with special needs. It is by becoming familiar with these new regulations that a parent can best support their child in advocating for appropriate educational services.

If you are the caregiver for a child or adult child with special needs, there are steps you can take to develop and implement a life care plan to improve the quality of life for you, your family and your loved one. Accessing vital information such as legal and medical records, and meeting with specialists with specific skills in this area are just the start.

We recommend that you begin by **addressing the primary issues**, meaning clearly identifying your main concerns, wishes and intent based on your individual situation. This step might include applying for government benefits, reviewing educational accommodations provided by a school, and/or assessing alternative care giver options.

Next, you'll want to **create a special care vision**. Your special care vision should answer questions like: what do you see for your child's future; what would you like her to be able to do; what do you want her to have access to; what kind of education will she be receiving; what will she do for recreation; in what kind of residence/housing will she live; what about her physical, intellectual, and perhaps spiritual

development? Take out your crystal ball and start looking at a year from now, 5, 10, and 20 years down the line.

Should something happen to you as the primary caregiver, you'll need to **choose a guardian or trustee**. "What if...?" scenarios can be painful to think about, easy to compartmentalize and ignore, but must be addressed. None of us will live forever and accidents *do* happen. Ask yourself: who would provide the best care for my loved one if I should no longer be able to? Attorneys and financial professionals that specialize in estate and long term care planning for special needs families are better able to provide you with helpful information and guidance in making such decisions.

Once you have created your vision and chosen your guardian/trustee, you'll need to **identify financial resources** that will be used to support your loved one. Some questions to ask include: will I use government benefits, and how much can they provide; can I use family contributions and how might they effect government benefits; should the monies be held in my name, my child's name, a trust?

By now, you'll want to consider having a team of resources, such as a special needs advocate, an accountant with experience in this area, and a special care planner as part of your team. In addition, you may consider a social or case worker as part of your team. These skilled individuals can provide additional information to help **determine plan/care costs**. By knowing what is available, identifying your resources, and seeking guidance from skilled professionals, you will be on your way towards developing a true life care plan for your loved one.

Ken Vinikoff is a Financial Professional, who has earned the Special Care Planner certificate from the American College as part of MassMutual's SpecialCare program and has made a commitment to serve people with disabilities and their families with their life care planning needs. Ken is a Registered Representative of investment advisory and financial planning services through MML Investors Services, Inc., a Massachusetts Mutual Life Insurance Company (MassMutual) subsidiary. Insurance Representative of MassMutual and its affiliates. Supervisory Office: 1660 W. 2<sup>nd</sup> Street, Suite 850, Cleveland, OH 44113, (216) 621-5680.



## Keith's Corner

Keith Paskoff, Nessa's first cousin, who suffered from Cerebral Palsy and cognitive delay passed away in 2003. The stories featured here are submitted by those who want to share their experiences and dedicate them to Keith's memory and his parents' unending effort to help him live his life as life fully completely as possible.

The following poems have been excerpted from *Our Book of Special Poetry* presented by the children of the Academic Fun and Fitness Camps. The director of the camps, Carol Richards, who is also the director of Northcoast Tutoring Services, believes education cannot afford a 12-week hiatus over the summer break. She puts her energy where her conviction lies and provides summer camps for children with disabilities. Summer programming should be a right of all special needs students.

Yo! I want to draw like many painters.  
Yo! Drawing makes me feel like a cloud.  
Yo! Drawing is like molding visual poetry.  
Yo! The rainbow in the sky is like a pencil  
in my hand.  
Yo! Drawings send you into the mind of  
the artist.  
Yo! Drawings can entertain like the music  
of every rock band.  
Yo! I want to draw like many painters.  
~Shasta  
*Brain G. (Shasta)*

I used to be sad.  
But now I am happy.  
I used to be boring.  
But now I am funny.  
I used to be a banana  
But now I am eating.  
What's up? I'm up. The sun is up  
laughing.  
Heaven rhymes with seven.  
Blue rhymes with two.  
Dinners nice if we have rice.  
Mom gives me rice twice.  
What's up? Two words I'm up.  
*Jared S.*

*Michael*  
I used to be a rhino but now I am an  
elephant  
I used to be a gator  
But now I am a hippo  
I used to be a monkey  
But now I AM A  
BABOON!!!!!!

*Ashley*  
The Sun  
The Sun gives us light and day.  
The Sun is big bright.  
The Sun is warm and shiny.  
The sun helps thing grow. And I love the  
Sun.

*Sam*  
I used to be a flag.  
But now I am a cab.

*Patrick*  
I am Special  
I am Special  
Look at me  
You will see  
Someone very special  
Someone very special  
It is me  
It is Me

## Estate Planning Seminar

Siegel & Agins, Co., LPA and the Michael Carter Financial Group will be presenting a seminar on estate planning for those with special needs. The seminar will cover issues such as identifying helpful resources, choosing a guardian or trustee, and searching for possible government funds or benefits. The seminar is free and open to the community. For more information, contact the offices of Siegel & Agins, Co., LPA at (216) 291-1300.

### Dates:

November 3  
Registration at 6:45pm  
Program begins at 7:00pm

November 15  
Registration at 9:45am  
Program begins at 10:00am

### Location:

Sheraton Hotel  
5300 Rockside Road  
Independence, OH 44131  
(216) 524-0700

## Specific Tools for Estate Planning

As the parent of an individual with a disability, planning for the future is a daunting, yet important process. You want to ensure that your loved one is well cared for after you are deceased. Planning is essential to protecting eligibility for a disabled loved one to Medicaid and/or Social Security benefits, as well as conserving your family's assets in general. Planning will also ensure that your final wishes are realized as you have memorialized them in writing.

There are many factors that should be taken into consideration when planning for your family and loved one with a disability. One should take into account family resources, members of the family and their ages, and the types of services needed by a disabled family member. Evaluating these factors will aid in determining the type of planning tools necessary for your needs.

After you have considered all factors and your final wishes, it is then important to look at the types of planning tools available to determine which best meet your needs. Today, there are a myriad of planning tools to ensure that your wishes are realized. The most common planning tools are *wills*, *living wills*, *powers of attorney*, and *trusts*. Through a will, a person is able to direct how their assets should be distributed upon their

death. A will also states who is to be guardian over minor children and appoints someone to care for your loved one with a disability. Living wills outline a person's medical wishes if she is in a permanently unconscious or vegetative state and can include "do not resuscitate" orders. There are two different types of powers of attorney: one that gives another the right to make financial decisions, and other that authorizes another person to make healthcare decisions. Finally, trusts, including several different types of *special needs trusts*, are popular tools used to protect benefits and assets. Trusts may be especially important when planning for the future care of a loved one with a disability as the correct trust can ensure that the individual's entitlement to benefits are protected while also providing funds to help maintain the lifestyle which you desire for your loved one.

Planning for the future needs of your family, including a loved one with a disability, is essential. Take time to consider your wishes and the needs of your loved ones and investigate which planning tools best suit your circumstances. If you already have executed documents, review them periodically to ensure that they still meet your family's needs and that they will protect the benefits your loved one with a disability is entitled to receive

*This newsletter is for informational purposes only and does not constitute legal advice or representation. Anyone needing legal advice should contact the attorney of his or her choice.*

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