



The Advocacy Center

Volume XIX, Issue IV
Winter 2011

The Bridge

Connecting individuals with disabilities and their families with resources, support and information



Annual Appeal Campaign Kick Off Events

The Advocacy Center hosted receptions at two locations on December 1, 2011, to highlight the Annual Appeal Campaign.

Receptions at Rochester and Big Flats featured opportunities to provide testimonials, letter writing to state and county elected officials, volunteer recruitment, and offering donations.

The Advocacy Center staff members were on hand to greet guests who came to show support for the agency and to make donations.

What's Inside...

This issue of *The Bridge* highlights Financial Planning- The Basics.



Changes in *The Bridge*

The above graphic denotes a change or new feature. Let us know how you like it... contact Maria Schaertel, Editor, Schaertel@advocacycenter.com or call (585) 546-1700, ext 271. The Bridge is created for you, your family, and community members! We value your ideas and comments.

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The Advocacy Center Faces Funding Cuts 2011 Annual Appeal Campaign Conveys Extra Urgency



The New York State Office for People with Developmental Disabilities (OPWDD) has eliminated funding for The Advocacy Center's Advocacy and Public Education Programs.

Executive Director Paul Shew and the Board of Directors appealed the decision but were unsuccessful in their efforts:

"OPWDD has decided not to restore funding for any information and referral programs funded through State Aid. Please understand that this decision in no way reflects on your program's merits, as the decision was made on a statewide basis". NYSOPWDD

Fortunately, the Monroe County Office of Mental Health historically has provided a matching grant to support these programs and has chosen to continue their support, for which we are very grateful. They noted that that the services provided by our programs "...are an extremely valuable resource to the community" and are "more important than ever for families."

But the state funding cuts are still large enough to affect programs at The Advocacy Center significantly.

If you have ever called The Advocacy Center looking for assistance, received the help of an advocate or attended one of our workshops or conferences, then you have been touched by these programs.

Please consider contributing to The Advocacy Center today to support Advocacy and Public Education Programs!

<http://www.advocacycenter.com/financialSupport.php>
The Advocacy Center, 590 South Avenue Rochester, NY 14620

Attn: Annual Appeal

Thank you!

Remember: contributions are tax-deductible.

Every little bit helps!



Austin Frank, a senior at Webster Thomas High School, painted *Creating a World That Works for Everyone* to illustrate The Advocacy Center's vision statement. The painting was introduced at The Rochester Annual Appeal kick off event and will be on display in The Advocacy Center offices.

Advocacy Center Upcoming Events & Workshops



"We want to hear directly from advocates – maybe they can answer questions in a column or discuss a current advocacy topic."

Introducing...

Is There an Advocate in the House?

QUESTION: I believe that my child needs Music Therapy, but my school says they don't offer it.

Laura: Did you request a Music Therapy evaluation? Remember, it needs to be in writing directed to your CSE Chairperson.

Julie: It's important to get the data that supports your request or that shows the need for the related service that you're requesting.

Laura: Music Therapy is a Related Service just like OT, PT, and Speech.

Julie: Yes, it's important that you request that your school district conduct an evaluation first to determine need. If your district determines that your child does not need Music Therapy or denies your request for an evaluation, then you have the right to obtain an independent evaluation.

Laura: You can go to our Parent Center website and download a sample letter for this evaluation request. www.specialedparentcenter.org. (Click on Resources, Documents, Sample Letters.)



Julie Buick



Laura Arrington

CSE Parent Member Training - Geneva City School District

January 17, 2012
9:30 AM to 2:30 PM

Would you like to learn more about the role of the Parent Member on the Committee on Special Education? Are you already serving in that role and would like more strategies for effective participation? This training introduces the role of parent member and offers strategies and techniques that will make you an effective parent member. The three modules contained within this training are intended to provide CPSE and CSE Parent Members with a best practices approach to the CPSE/CSE process and their role as a Parent Member that is consistent with New York State law and regulation. Geneva City School District, 400 West North Street, Geneva NY, 14456

Offered free of charge. Registration is required.

To register call (585) 546-1700 ext. 399 or visit www.specialedparentcenter.org.

Everything You Wanted to Know About the CSE Process but Were Afraid to Ask

January 19, 2012
7:00 PM to 9:00 PM • Webster, NY

When your child has special educational needs, you will be working with your school district's Committee on Special Education to determine your child's needs and services provided to address those needs. Find out who is on the committee and the parent's role on the committee; Learn about the annual review and how to prepare for it; Understand what is on your child's IEP; Learn how to collaborate with school personnel. To be held at Webster Thomas High School Library, 800 Five Mile Line Road, Webster, NY 14580.

Offered free of charge. Registration is required. To register call (585) 546-1700 ext. 399

The Advocacy Center is pleased to announce for professionals

Pro-Social Behaviors and Sexuality: Teaching Pro-Social Behaviors During the Journey to Adulthood... What Professionals Need to Know

Teaching individuals with disabilities about sexuality is important in promoting independence, personal safety, healthy lifestyles, healthy relationships, and social inclusion. Professionals will leave this workshop with the information and confidence they need to address the topic of sexuality with children, teens, or young adults with disabilities.

January 18, 2012 1:00 PM – 3:00 PM

The Advocacy Center, 590 South Avenue, Rochester, NY 14620

Presenters: Julie Buick and Laura Arrington

Registration and payment are required

Register by January 10, 2012 (Limited Space)

To register, phone (585) 546-1700, ext. 399 to reach our registration line or

Complete an application at

http://www.advocacycenter.com/pdf/01182012_Sexuality_professionals.pdf

Financial Planning – the Basics

The Social Security Administration (SSA) administers two federal programs:

#1 SSI - Supplemental Security Income

SSI makes monthly payments to people with low income and limited resources who are 65 or older, or blind or disabled. **Your child younger than age 18 can qualify if he or she meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits.**

Eligibility

- The child must not have gross wages greater than \$1,010 a month in 2012.
- The child must have a physical or mental condition, or a combination of conditions, that results in "marked and severe functional limitations."
- The child's condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.

For disability purposes in the SSI program, a child becomes an adult at age 18, and different medical and nonmedical rules are used when deciding if an adult can get SSI disability payments. For example, the income and resources of family members are not counted when deciding whether an adult meets the financial limits for SSI.

If your child is already receiving SSI payments, the child's medical condition when he or she turns age 18 must be reviewed; the adult disability rules are used to decide whether an 18-year-old is disabled.

- If your child was not eligible for SSI before his or her 18th birthday because you and your spouse had too much income or resources, he or she may become eligible for SSI at age 18.



Quick Review

- Monthly payments made to children or adults with disabilities who meet income requirements.
- At age 18, only the individual's income is counted, not the parent's.

#2 SSDI – Social Security Disability Insurance

Social Security Disability Insurance (SSDI) provides benefits to individuals who are disabled or blind. **SSDI is funded by employees' contributions** to the Social Security trust fund, or the Federal Insurance Contributions Act (FICA) social security tax paid on yearly earnings.

The SSDI program pays benefits to adults who have a disability that began before they became 22 years old. This is considered a "child's" benefit because it is paid on a parent's Social Security earnings record.

For a disabled adult to become entitled to this "child" benefit, one of his or her parents:

- Must be receiving Social Security retirement or disability benefits; or
- Must have died and have worked long enough under Social Security.

These benefits also are payable to an adult who received dependents benefits on a parent's

Social Security earnings record prior to age 18, if he or she is disabled at age 18. This disability decision is made using the disability rules for adults.

SSDI disabled adult "child" benefits continue as long as the individual remains disabled.

Your child does not need to have worked to get these benefits.

Eligibility

Eligible individuals are evaluated using earning guidelines and substantial gainful activity (SGA) work ability, as well as disability guidelines. SGA is used as a factor to decide if disability insurance should continue after the individual is already receiving benefits.

Quick Review

- A monthly benefit for people who have worked in the past and paid Social Security taxes and who are unable to work for a year or more because of their disability.
- If a parent retires, becomes disabled, or dies while a child is under age 18, the child may be eligible to receive SSDI. A child who is disabled can continue to receive SSDI after age 18.

The Special Needs Trust - Info for Parents

The special needs trust can be your primary savings tool for your child's future. It allows you to properly transfer savings to your child without jeopardizing his or her ability to receive government benefits.

Also referred to as a "supplemental care trust" the special needs trust provides a way for you to supplement government benefits such as Medicaid and Supplemental Security Income (SSI). The trust can be set up so it functions while you're alive, or begins to function after your death.

First you select a trustee—someone you completely trust and who can properly manage money. If the trust is to function while you are alive, the trustee distributes money from the trust to your child in ways that don't disqualify your child from government benefits. If the trust is to function after your death, the trustee facilitates the transfer of money from your estate into the trust, then helps manage and distribute the money according to your wishes.

The most important benefits of the trust are maintaining your child's financial well-being and his or her long-term eligibility for government assistance. It has another benefit, though. Through this trust, friends and family can make gifts of money, also contributing to the financial well-being of your child.

-PACER Center, *Possibilities* <http://www.pacer.org/publications/possibilities>



Quick Review

- Can also be called a "Supplemental Needs Trust."
- A savings plan for your child with a disability who needs help handling money. (Not all people with disabilities need this kind of help.)
- You need an attorney or financial planner to set it up and help decide how you want to put money into the fund.

Quick Review



- At age 18, the law says we are all adults and capable of making decisions on our own. But some individuals with developmental disabilities may not be able to make decisions.
- Parents or others may get legal permission from the Surrogate Court to become the decision-makers, "guardians," for the person with a developmental or intellectual disability who is 18 or older.
- Depending on the type of guardianship, the guardian may make decisions about health care, money, living arrangements, recreation, or property, among other things.

Guardianship

Article 17A of the Surrogate Court Procedure Act was enacted in 1969 and amended twice in subsequent years. It permits parents or any other concerned party to petition the Surrogate Court to be appointed guardian of the adult who is disabled. By being appointed guardians, parents can legally continue their authority beyond age 18.

The guardian takes on the decision-making ability for the person who is intellectually/developmentally disabled, especially as it relates to elective medical surgery. However, many physicians may accept the signature of the parent for surgery even if he/she is not the guardian; this is totally at the discretion of that physician. The law has been amended to explicitly provide a guardian with the authority to make health care decisions including decisions regarding life-sustaining treatment under certain circumstances.

The petitioners for guardianship can name a standby guardian and an alternate standby guardian. These individuals will assume responsibility after the death of the preceding guardian.

Anyone may apply to be the guardian of an adult who is intellectually/developmentally disabled. In some instances, even private agencies may be appointed guardian of a person if permitted to do so in their articles of incorporation.

-The Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC)
<http://cqca.ny.gov>

Letter of Intent

Our children with disabilities need our love, devotion, energy, compassion and patience. However, this is not enough. Their special needs also demand special planning. Parents of children with special needs know that their child will require lifetime care, care that can be both complex and expensive.

Without proper planning, if you die suddenly, no one will know how to care for your child. Often, the parents are the only ones with the specific knowledge of the child's needs, medications, physicians, likes/dislikes, routines and habits. You must ensure that a transition will be as seamless as possible, to protect the child from dislocation and disruption and assure a continuum of care and safety.

In short, prepare a user-friendly road map, sometimes called a "Letter of Intent", containing as much information as possible on caring for the child. Give the roadmap to the person who will care for your child when you cannot. This way, whoever takes over as caregiver will have the necessary guidance and information to care for the child from the very first day.

Where to begin? Pretend you are writing a letter to the caregiver. At a minimum, your letter must address the following areas.

- 1. Medical / Physical.** Specify in detail the nature of each of the child's disabilities. Provide a complete medical history starting from early childhood. If possible, list names and contact information for every doctor the child ever consulted. Identify current physicians and other care providers, medicines (with a schedule for dispensing them), pharmacies where the prescriptions are held. Provide addresses and telephone numbers. Specify the child's eating habits. What is her clothing size and taste? What kind of food does she like or dislike? Can she dress, feed, move, bathe or toilet herself? If not, what type of help does she need? Does the child have special transport needs?
- 2. Psychological / Emotional.** Identify any psychological or emotional issues the child may have. Does he anger easily? Is he shy? If the child is receiving therapy, include details on the therapist and the type and frequency of treatments.
- 3. Safety.** Is the child safe to leave alone? Are there any alterations to living arrangements that are currently necessitated by the disability or may become necessary if the disability worsens? What other steps must be taken by the caregiver to protect the child?
- 4. Social.** What does the child like to do? Read? Watch TV? Play video games? Listen to music? Paint? Travel? Equally importantly, what does the child not like to do. If the child has friends, identify them, with addresses and telephone numbers.
- 5. Spiritual.** Does the child have a faith life? Identify the spiritual counselor (rabbi, minister, priest) with contact information. If the child does not have a spiritual counselor consider establishing a relationship among yourselves, your child and a counselor. This will assure the child will have spiritual comfort upon your passing.
- 6. Economic.** Will the child have money to live, to pay medical expenses? Where will the money come from - inheritance, government benefits? Does the child have a job? If so, where, and what are the work hours? Where will the child live? Is the child receiving any government benefits? If so, which ones? Provide details on the benefits, along with contact information at the relevant agencies. If the child is expecting to inherit money from parents, grandparents or others, the inheritance may cause a loss of any government benefits that are based on financial need, such as Supplemental Security Income (SSI) or Medicaid. If so, have provisions been made for special needs trusts or other vehicles to receive the funds, instead of the child, in order to avoid losing those benefits?

-Excerpt from *Planning for Children with Special Needs* by [Raymond J. Falcon, Jr.](#) Last Updated: 8/29/2011
<http://www.specialneedsanswers.com>



Quick Review

- A letter parents write for future caregivers of their children.
- The letter provides detailed information about your child's needs, interests, and preferences in all aspects of their lives.



Five Quick Tips for the Family with Special Needs

By James Traylor, Special Care Planner
Financial Services Professional
Financial Architects – MassMutual
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<http://www.financialarchitectsupstate.com/>
james_traylor

Review Beneficiary Designations

Retirement accounts, life insurance policies, and other investment accounts all have beneficiary designations. Should an SSI or Medicaid recipient receive these assets, their benefit could be jeopardized. It is good practice to review employer provided benefits in addition to private accounts to verify that the beneficiary arrangements are updated.

Beware of Custodial Accounts

Placing assets in a custodial account for a child with a disability is, in effect, no different than an outright gift of the assets to the child; both actions may equally jeopardize the child's government benefits.

Communication with Family

Other family members may intend to leave assets to a child with disabilities. It is very important to communicate with these family members to avoid potential disqualification for government benefits.

The Special Needs Trust

A properly drafted Special Needs Trust is the only available tool, other than disinheritance, that allows money to be put aside for a person with a disability without it being considered a 'countable asset' offsetting government benefits such as SSI, Medicaid, vocational rehabilitation and subsidized housing.

Funding a Trust

If the intent of a family is to assure that funds are available after the parents have died, it may be prudent to purchase permanent insurance on the life of the parents with the Special Needs Trust as the beneficiary. As long as the policy is not owned by the child, it cannot be deemed a "countable asset" that jeopardizes the benefits that the child is receiving.

"How about combining Trade or Connect and News You Can Use under one new heading: Resources?"



Introducing...

Resources

Social Security Administration www.socialsecurity.gov
or 1-800-772-1213 - Call 7 a.m. to 7 p.m., Monday through Friday for answers to specific questions. You may access information by automated phone service 24 hours a day. If you are deaf or hard of hearing, call TTY number, 1-800-325-0778.

The Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC) <http://cqc.ny.gov>

Neighborhood Legal Services, Inc. www.nls.org

Possibilities: A Financial Resource Book for Parents of Children with Disabilities, National Endowment for Financial Education; PACER Center, 2011 (PACER is Parent Advocate Coalition for Educational Rights, located in Minneapolis, MN, serving families across the nation.)

For people who receive either SSI or SSDI benefits and want to work.

Social Security – Red Book <http://www.socialsecurity.gov/redbook> - also includes Spanish language version.

American Institute of CPAs—Personal Financial Planning Section
An organization for CPAs who provide estate, tax, retirement, risk management, and investment planning advice to individuals: www.aicpa.org; 1-888-777-7077.

Financial Planning Association (FPA)
The largest organization of financial planners who provide financial advice to individuals and are committed to upholding the highest standards of professional competence, ethical conduct, clear disclosure to the individuals they serve: www.fpanet.org; 1-800-322-4237.

The National Association of Personal Financial Advisors (NAPFA)
A leading organization of financial advisors who provide fee-only financial services: www.napfa.org; 1-847-483-5400.

Special Needs Alliance (SNA) is a national, not for profit organization of attorneys dedicated to the practice of disability and public benefits law. www.specialneedsalliance.com
See current and past issues, *The Voice Newsletter*

Special Needs Answers A community resource provided by Academy of Special Needs Planners. www.specialneedsanswers.com

Something to Think About...

Percentages of parents who reported the following about Life Care Planning

- Designated a Guardian – 30%
- Created a Special Needs Trust – 27%
- Written a Letter of Intent – 10%

From *The Easter Seals Living with Disabilities study*, sponsored by Massachusetts Mutual Life Insurance Company (MassMutual), conducted by Harris Interactive, 2007.



"We want to hear from Dads, Grand Dads, Step Dads, any dads. We Moms are tired of doing all the talking."



From the Editor

Financial planning for our children with disabilities can only happen when we acknowledge that we parents and caregivers will not always be around for them. And they need to have resources to be able to go on without us.

If we get over our fear and discomfort and start planning, we can actually make the future better for our kids. If you have not begun financial planning, this is a great time to start.

A group of parents, community members, and Advocacy Center staff members gathered on October 5 for The Bridge focus group. We enjoyed a great exchange of ideas and reflected upon what is working in the newsletter and discussed possible changes. The changes that you see in this issue come directly from that meeting. We invite your ideas and feedback – please contact Maria Schaertel, The Advocacy Center, 590 South Ave, Rochester, NY 14620 or Schaertel@advocacycenter.com. A few more changes to come...

This is a difficult financial time for The Advocacy Center. Due to state funding cuts, Executive Director Paul Shew together with the Board of Directors have been studying ways to handle the cuts.

Please consider making a donation today. You may donate at our website: <http://www.advocacycenter.com/financialSupport.php> or mail a donation to The Advocacy Center, 590 South Avenue, Webster, NY 14580 or phone Seneca Brashear at (585) 546-1700.

Thanks to those of you who have already responded to this urgent appeal.

Happy Holidays and Happy New Year to all!! When you write a Letter of Intent for your children, don't forget to include all those holiday family, faith-based, and community traditions!!

Maria Schaertel

Introducing...

Dad's Corner

By Jim Swart, Partners in Policymaking Class of 2004

June 3, 1998 – Memories and Other Wonderful Moments

Miss a minute, miss a moment. This metaphor was brought to my attention during the Capital Region Fathers Forum in Albany by Kenneth Braswell, Executive Director of Fathers Incorporated, who gave an inspiring keynote to twelve courageous dads who have a child or children with a developmental disability.



Miss a minute, miss a moment. What Mr. Braswell was trying to tell us is that as dedicated, committed, caring fathers we need to be as present in our child's life as we can. Fathers are key role models for children so families in which a father is actively involved in the life of their child benefits the entire family.

Miss a minute, miss a moment. When Maddie was born in 1998 and after the diagnosis of Down syndrome was confirmed, my wife, Veronica, and I came to a decision that Maddie was to be raised as "normally" as our older daughter, Cassie. Maddie would attend school, have friends, and grow up to be a wonderful young lady and adult. We can control the known factors of Maddie's life but the parts that would be spontaneous are what may become the best memories of all.

Miss a minute, miss a moment. As a family we attend the Hildene Craft Festival in Vermont. I was shopping separately and returned to meet Veronica and the girls. Maddie was little and in a stroller at the time. I was talking to Veronica when I noticed a young lady bend down and speak to Maddie. I did not know who she was so I said hello. When she looked up and said "Hello, my name is Sue" it was obvious she had Down syndrome. Her mother came over and said she picks up on those type of things and mentioned that Maddie was beautiful. Then she said something that would come evident later in Maddie's life. The mother said Maddie and Sue were "sisters of the heart". I was not sure what that meant until years later. Maddie has a kindness towards people, especially babies and Sue was expressing that same kindness. They truly are sisters of the heart.

Miss a minute, miss a moment. Many families do not plan to add disability to their lives but when disability arrives it brings the voice of fear, grief, denial. Fathers need to support our families to be courageous because we can't prepare for or control disability, we just need to react in the proper way, be curious, observant, and listen deeply with our hearts. Disability makes other people's lives better without even knowing it. Maddie makes that very clear when I come home and she says "Daddy??", then runs to me and gives me a big "Maddie" hug.

Miss a minute, miss a moment. Dads, be there for your child. You never know when that minute or that moment will happen.



"For those of us new to the Special Education System, we are overwhelmed by the use of acronyms and terms that all of you use so frequently. Please explain some basic terms and resources in each issue."

Introducing.....Newbie Notes

Do you suspect your infant or toddler has a delay in development? You may want to explore Early Intervention.



Early Intervention

- A voluntary developmental evaluation and services program offered by New York State and administered locally by Child and Family Health Services of the Monroe County Department of Health.
- Serves children from birth through 2 years of age and their families where there is a high risk of delay, a suspected delay in development, or a confirmed diagnosis of developmental disability.
- Evaluations are conducted to determine eligibility.
- A variety of therapeutic and support services are offered to eligible infants and toddlers with disabilities and their families.
- If a child is found not eligible, parents can request "developmental monitoring," a questionnaire mailed to parents to help educate and empower parents on child development.



For more information, call (585) 753-KIDS or visit <http://www2.monroecounty.gov/hd-ei-home>

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www.advocacycenter.com

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