

The Bridge

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

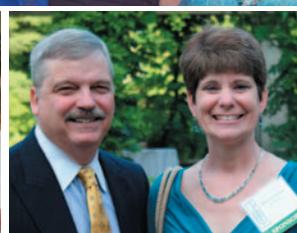
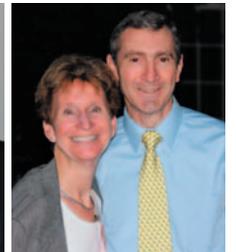


ART & JAZZ



An Evening of ART & JAZZ

The Advocacy Center's annual fundraiser featured music, art, friends, and supporters at George Eastman House on June 2. Congratulations to The Advocacy Center planning committee, board members, staff, family, and friends for an amazing event!



What's Inside...

This issue of *The Bridge* highlights The Power of Social Connection.

Community Award Winners Page 2

The Power of Social Connection Page 5



2012 Community Award Recipients



2012 Community Award Recipients: (Left to right)

- Kelsey O'Sullivan**, Student Award
- David Hamilton**, Community Impact Award
(not pictured, Bart Roselli and Michelle Picardo)
- Tricia Brown**, Founders Award in honor of Jeanne Krautwurst
- Beth Platt**, Corporate Support Award on behalf of
Beth Platt and Associates beside Adam Anolik, Board President
- Brady Dean**, Self Advocacy Award
- Jan Whitaker**, Community Inclusion Award
- Jeanne Ricigliano**, Barbara Bryson Award
- Jackie Bartell**, Community Education Award

NEW!

Nominations for Community Awards

accepted year-round!

Do you know someone who stands out in service and commitment to people with disabilities?

Or maybe a self-advocate whose work and life direction you admire?

The Advocacy Center now accepts nominations for Community awards year-round. Award winners are honored at our annual fundraising event. Don't miss the opportunity to honor a special parent, teacher, community member, or self advocate!

Please contact Rick Wright for further information at (585) 546-1700 or wright@advocacycenter.com.

Is there an Advocate in the House?



QUESTION: I have invited my daughter's classmates over for birthday parties, movies, and lunch but they never reciprocate. They always come over and have a great time – why don't they invite her over to their houses? I think I am more hurt about this than she is. My daughter is 9 years old, has CP (Cerebral Palsy) and uses a wheelchair. What can I do without making my child appear desperate for social invitations?



Martiza Cubi,
Bilingual
Parent Education

Maritza: Friends and socializing can be tough issues. What I have done is to meet with the parents and discuss getting together for a play date, meeting at the mall, or going out for ice cream. Socializing does not always have to take place at someone's house. Though it sure would be great if every house was accessible, but that just isn't possible.

Norann: So one practical solution for getting together is a portable wheelchair ramp. I just purchased a used set that cost \$65. Just remember that you need a vehicle to transport it, but if you have someone in your home who uses a wheelchair, you will probably already have a wheelchair van.

I agree it is important to meet with the parents. So the next time you invite the child over, make sure to invite the parent or family to come in and sit down and talk over coffee or lunch. Speak directly to them and let them know about your child. Help them become comfortable. It's hard.

Somebody that has never cared for a child using a wheelchair may not be comfortable with the thought of caring for that person. Be open to their questions. In their heads, they are thinking, "When this child comes to my house, how am I going to take care of him? What if he needs to use the bathroom? What if he needs help eating?" You have to be open with them and let them it's OK to ask about anything. Just talk.



Norann Shiner, Advocate

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Advocacy Center Upcoming Events & Workshops

What is a Webinar? How do I use it?

A webinar is a “web-based” seminar. A webinar can be a lecture, a presentation, a workshop or a meeting that is held on the Internet. You need to use a computer and have Internet access to join in. You can hear the presenter and see the presenter slides right on your computer. You will not be able to see the presenter and no one can see you. You need to register in advance if you want to participate in a webinar. Notice the start time and plan to join the webinar 5-10 minutes before. That will give you a few minutes to familiarize yourself with the webinar viewer so that you may participate by submitting questions. Once your registration is approved, you will receive an e-mail confirmation.

Vicarious Trauma: The Cost of Caring

August 8, 2012 - 8:30 AM to 12 PM
Nazareth College @ The Forum,
4245 East Ave, Rochester, NY 14618



Learn how situations you encounter professionally can affect your health and relationships with family, friends, and colleagues.

Gain strategies to keep yourself and your organization healthy. This workshop is ideal for social workers, nurses, service coordinators, ministers, supervisors, educators, caregivers, and anyone in a caring profession. Fee: \$49. To register and pay online, locate this event on our website calendar: www.advocacycenter.com/calendar.php

Questions?

Call 585-546-1700 ext. 267 or email registration@advocacycenter.com

Presented by

JoAnn Jankoski, EdD, MSW, MS

Webinar Opportunities For Parents

Join us from home, join us from your office – no need to travel

Manifestation Determination

Thursday, August 9, 2012 [Register for this webinar](#)
12:30 – 1:30 pm

This webinar will provide a general overview of Manifestation Determination. Participants will gain an understanding of what a manifestation of a disability is, they will learn how to prepare for the Manifestation Determination meeting, and they will gain an understanding of the unique circumstances that surround each of these situations.

Organizing Special Education Records

Tuesday, September 18, 2012 [Register for this webinar](#)
6:00 – 7:15 pm

Advocacy is at your fingertips when your child’s education records are organized. This workshop will offer tips and techniques for organizing reports and evaluations. Participants will learn how to organize educational records and use a record keeping book. This workshop will assist you in becoming more organized in the planning of your child’s education and the CPSE/CSE process.

Apoyo de los Padres: Una Colaboración entre el Hogar y la Escuela Presentado en Español

Jueves, 27 de Septiembre 2012 [Regístrese para este Seminario](#)
12:00 pm – 1:00 pm

(Parent Involvement ~ A Collaboration between Home and School- Presented in Spanish)

Thursday, September 27, 2012 [Register for this webinar](#)
12:00 pm – 1:00 pm

Las familias tienen una influencia importante en el logro de sus hijos en la escuela y a través de la vida. La investigación muestra que cuando los padres están envueltos, los estudiantes tienen calificaciones más altas, puntuaciones más altas en los exámenes y un nivel más alto de graduación; mejor asistencia a la escuela; mayor motivación; mejor autoestima; y un nivel de suspensión más bajo.

Este taller ofrecerá a los participantes con las herramientas para desarrollar una relación positiva y colaboradora entre familias y escuelas. Los participantes aprenderán habilidades comunicativas y estrategias para apoyar el éxito educativo en el hogar y en la escuela.



Webinars are free to parents, family members, and individuals with disabilities, our target audience for these events. Professionals may attend for a fee of \$25. We also offer webinars specifically for professionals. For more information please contact Colleen Brown at brown@advocacycenter.com or (585) 546-1700 ext. 267.



Is There an Advocate in the House?

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Maritza: If you are the parent of a child with these kinds of restrictions, you need to be able to talk about what your child needs. And of course your child’s privacy must be respected. But there are things that you can talk about.

If your child is going to build a relationship with someone, it’s important that you support your child’s social and emotional needs. During this process you may get to develop a relationship with the parents. You want to allow them to feel comfortable with your child. They may also grow to be a support to you and your child.

For example, I have known parents who, because they wanted my son included at a gathering, planned the activity outside or at an accessible building so that he could join in.

I have built relationships with parents who are now comfortable assisting my son. You have to be willing to allow them to help. And you also have to have a conversation with your child to find out how comfortable he or she will be accepting assistance. Your child’s needs will change over time. A child’s perspective and choice are different from a young adult’s.

Norann: When it comes to talking with parents, you may have to be the one to bring up topics of personal care. They may just be too uncomfortable to bring it up.

Another option to consider is to send an attendant or nurse to care for your child. For instance, when my son went to camp, he did not want me there. Just like any other young person seeking independence from parents, so it is with our kids with disabilities. So I sent his nurse with him and she knew when to assist him and when to back off and let him go. That’s important.

If you and your child choose to use a nurse, and your child is going to someone’s house, it’s important that you talk to the parents and find out if they are OK with that.

Maritza: Yes, there are resources out there. For instance, depending on the programs that your child qualifies for, your family may choose a personal caregiver, someone that you know and trust, to provide support for your child. Having and knowing the resources are so important. You can help support your child before building those new relationships.

Norann: Another thing to consider is that some people may not be accepting of your child. You have

to respect their wishes and feelings and accept that. You don’t know what their experiences have been in this area. Unfortunately, one bad experience may wipe out all the good ones.

I have had experiences with my son not being accepted, and he knows it. That is hard. If I know of a situation where he is not wanted, I will not put him in that situation. He feels it; he knows it; and he’s angry because he doesn’t understand it.

And you can’t always depend on your children telling you. Sometimes they act it out because they don’t know what they’re feeling. You have to keep your eye on that.

Maritza: Yes, there are those people who will not be accepting. I tell my children that the people who are not accepting are the ones who are losing out because they are not open to meeting such a wonderful person. I also try to help them remain positive and concentrate on the friends that they do have. If someone doesn’t like you, it is what it is – Do not focus on the negative – it’s not healthy.

Maritza: You have to let go of the fear of “appearing desperate.” Instead, concentrate on what is important to your child. Is it worth the effort to open a door? Open the door to an new experience!

Workshops offered in Spanish

The Advocacy Center puede ayudarlo y guiarlo a obtener las ayudas para que su hijo/a pueda tener éxito. Los servicios son gratuitos para los padres e incluyen; apoyo a través de información, referidos, talleres, abogacía, y más.

En el **The Advocacy Center** actualmente ofrecemos los siguientes talleres en español:

- The Advocacy Center -Visión General
- Pasos de Abogacía 101
- Construyendo su Cuaderno Médico
- El Proceso del Comité de Educación Especial
- “Bullying”- Estrategias de Intervención
- Estrategias para una Comunicación Efectiva
- Desarrollando una Visión
- La Escritura del PEI
- Educación Especial
- El Apoyo de Padres
- Conocimiento de Discapacidades: Mi Inspiración

Para más información favor de contactar a Maritza Cubi al (585)546-1700 o cubi@advocacycenter.com.

The Power of Social Connections

Dr. Al Condeluci, PH.D., CEO of UCP-CLASS in Pittsburgh, PA, teaches about "Social Capital"- the power and value of relationships. *In his books, university lectures, consultations, and in world-wide presentations, he describes how people with disabilities often have less social capital and how damaging that can be. Research shows that health, happiness, jobs, advancement in work, and longevity are all related to social capital.

Parents, educators, and health care providers focus on providing support to meet important developmental and educational goals. But one crucial area that is often overlooked, maybe because it can be difficult to achieve or requires extra cultivation, is social engagement – the need for friends and connectedness.

Quick review

Having friends is important!

People with friends are healthier, happier, more successful at work, and live longer.

How do children and adults with disabilities meet new people and make friends?

Dr. Condeluci describes four steps in helping to develop relationships:

- 1. Find what the person has in common with others.** That could be any interest or activity: reading, golf, computers, music, dance, nature walks, drawing, movies, or video games, etc.
- 2. Find a Matching Community Venue that Meets on a Regular Basis** – a club or group in the community that already does this activity. It might be a book club, drumming circle, gardening club, or hiking group.

- 3. Understand How the Group or Club works** - What is expected of people in this group? How do the members behave? What jargon do they use? Share this information with the person as it relates to him or her.
- 4. Find a "Gatekeeper"** – a person already in the group who can introduce a new person to the group. Maybe your neighbor or co-worker pitches for a community softball team. He could be a gatekeeper for your daughter who wants to play softball. Everyone in the group knows the gatekeeper and will readily accept the new member if the gatekeeper brings the person in.

Traits of Positive Gatekeepers

- Positive people- they smile
- Reach out to people
- Willing to take risks
- Usually flexible
- Often right brain thinkers (creative, sees whole picture, outside of the box thinker)
- Often female



Dr. Al Condeluci, PH.D.
CEO of UCP/CLASS
(United Cerebral Palsy/Community Living and Support Services in Pittsburgh)

**Editor's Note: You will find a wealth of information provided by Dr. Condeluci. One great accessible resource are his presentations posted on You Tube - mini-lessons (5-10 minutes each) packed with information about the importance of relationships. www.youtube.com. Just search for "Al Condeluci."*

Thinking outside of the box:

Do you know someone who could be a positive gatekeeper?? Let's nurture and encourage our gatekeepers, at any age or in any social situation. Here are some ideas:

- Try suggesting to a child to think of somebody at school that he or she might invite to his lunch table. A fellow student who is normally sitting with an adult helper or alone may come to mind.
- Drop a line to your school counselor or community mentor letting him know that your child could be a great buddy to someone at school or in the community.
- Suggest that a teen invite a student to meet her at the next football game, tennis match, or community event, depending on the interest that person may display.
- For adults, the next time your church or book club has a gathering, bring a friend along who is uncomfortable joining in alone.

Ways to Promote Friendship and Social Activity

TIES (Together Including Every Student)

A great resource to support students with developmental disabilities (age 8-21) who want to participate in school and/or community activities is TIES (Together Including Every Student). TIES trains student volunteers to provide effective, natural support. For example, if a student wants to attend a school club but needs support to participate, a TIES volunteer will meet the student at the activity and provide support and companionship. Students and young adults with disabilities who were never able to attend an after-school or community activity because they needed support or that support was provided by an adult or parent, can now attend any organized activity of their choice with the support of a peer.

In addition to supporting activities based on individual needs, TIES also finds creative ways to include participants and volunteers in activities based on their interests with drumming circles and Outrigger Canoeing.

Kathy Costello answers some questions about TIES.



TIES is growing – describe recent developments. TIES started in 1997 in the Webster and Brighton Central School Districts through a grant from the DDPC. Now through funding from Family Support Services, TIES is in 30 school districts in the Finger Lakes and Western NY regions. TIES has enriched the lives of many participants, families, volunteers and activity leaders in all these communities.

Since TIES is available through school districts – does this mean students can only access TIES during the school year? TIES is available all year, not just during the school year. If a student would like to attend an activity during the summer in their community, they can do so with the support of a TIES volunteer.

What about school districts that don't sponsor TIES? How can parents advocate for TIES? Is there another way to get this type of peer support for students? TIES is unique in many ways. A TIES Coordinator in each school district recruits and trains student volunteers, sends application to participants, follows up with families to gather more information and identify activities, creates an individual support plan to share with the volunteer so they have the best strategies for success and then the Coordinator keeps in touch with families, volunteers throughout the year to make them aware

of opportunities. If TIES is not in your school district, please contact Kathy Costello, TIES Program Director, at costello@advocacycenter.com and she will assist you in working with your school administrators to implement TIES.

For a complete listing of TIES coordinators and school districts, please visit <http://www.tiesprogram.org/>. For additional information, please contact Kathy Costello, TIES Director, at costello@advocacycenter.com.



Plan a Summer Gathering for Adults

Gather adults together for an evening of bocce or volleyball in the backyard. Then get together in the kitchen and make;



Two Minute Party Punch

- 2 (2 liter) bottles ginger ale
- 2 (2 liter) bottles strawberry flavored soda
- 2 cups lemon sherbet
- 1/2 (16 ounce) package sliced frozen strawberries

Pour the ginger ale and strawberry soda into a punch bowl. Scoop the lemon sherbet into the punch bowl, and stir in the sliced strawberries.

Resources



Books by Al Condeluci:

Together is Better: Creating a community where each belongs, Cultural Shifting, Interdependence, Beyond Difference

Please see Al's website for a complete bibliography, as well as articles, and more. <http://alcondeluci.com/>

Social Networking Websites

The Friendship Network, for adults with Down syndrome: http://www.dsagc.com/resources_friendship_network.asp

For individuals with Autism, family, and community members:

- <http://www.weareautism.org/>
- <http://www.wrongplanet.net/>
- <http://www.autismspeaks.ning.org/>

Newbie Notes

Want to facilitate friendships at school?

Take a look at the Karen Gaffney Foundation website and learn about Karen's Friends First program. <http://www.karengaffneyfoundation.com/FFprogram>

Another similar program combining social activities with service is K-Kids (Kiwani's Kids) <http://kiwaniskids.org/>

Dad's Corner

“Being Alex’s father has allowed me to appreciate each achievement and milestone at such a deep level. Alex has an ability to brighten each day by giving the best hugs. I am proud to call him my son.”

-Nick Chervenak



Educational Legislation

Senate HELP Committee Plans Hearing on Restraint & Seclusion NYS

The lack of protections for all students limiting the use of aversive behavioral strategies, restraint and seclusion has proven to be a disastrous missing component of our national education policy for children and parents. It is time to align federal education policy *with all other federal policy related to human services* and for the nation’s youngest, most vulnerable citizens. The Keeping All Students Safe Act, S. 2020, represents a culmination of years of advocacy against abusive behavioral interventions that dehumanize and harm students. The time to pass this bill is now – we can no longer endure harm to vulnerable children as a result of abusive practices when decades of research equip education professionals with positive, safe and effective alternatives.

Ask your Senators to co-sponsor S. 2020 and your Representative to co-sponsor HR 1381 (which has similar provisions) by visiting www.congress.org and entering your zip code, which links you to the correct e-mail address.

Simply write “Please co-sponsor S. 2020” or “Please co-sponsor HR 1381” and, if you can take the time, include a brief paragraph about yourself and why you care about this issue.

Pictured below: Rochester area Partners in Policymaking graduates gather in the George Eastman House gardens during A Night of Art and Jazz.



From the Editor

Dear Parents,

No one can tell you what educational course is right for your child. We pursued this option: to have our son remain in his home school as much as possible rather than go to a segregated setting. This was the best decision for Nick and for our family. Judging from Nick’s stride to accept his diploma and his pride in showing it off, I think he is happy.

If this is your choice for your child, then we are here to tell you it can be done. Whatever your goal is, find other parents and educators who share your vision, then go for it.

Maria Schaertel, Editor

* * * * *



Dear Nick,

I am so proud of you as you graduate from high school! I want you to know how happy I am for you and how exciting your future will be. Dad, Andrea, and I will always be here for you, your “happy family.”

I love being on this life journey with you. Sometimes it can be tough.

You are a great son, a great brother, a great musician, a great friend, and a great traveler. Let’s keep going!

Love, Mom



NYS Partners in Policymaking News

The 2012 class of NYS Partners in Policymaking is well underway. Approximately 68 individuals are participating in the course using a blended distance learning format. Applications for the 2013 class will be available at <http://www.nyspip.org> in the fall of 2012.



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The Advocacy Center Presents

**William Stillman: Demystifying Autism
& other Neurological Differences**

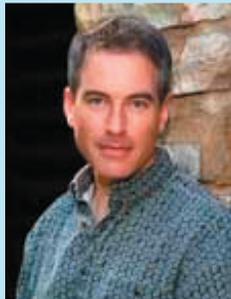
Co-Sponsored by Nazareth College

Thursday, October 17, 2012 9 am—4 pm

Registration: 8:30 am

Location: Nazareth College @ The Forum
4245 East Avenue, Rochester, NY 14618

Space is Limited - Registration deadline 10/10/12



William Stillman

For more information contact: Colleen Brown brown@advocacycenter.com

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the Marketplace



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