

The Bridge

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



What's Inside...

This issue of *The Bridge* highlights

Health Wellness

 **Is There an Advocate in the House** Page 2

 **14 Weeks to a Healthier You!** Page 4

 **Out and About Stay Active this Winter** Page 5
See a listing of local indoor and outdoor activities

 **Dad's Corner** Page 6

 **Partners in Policymaking News** Page 8



UPFRONT & PERSONAL

Interview with **Jessica Merriam** A Partners in Policymaking Graduate

Tell me about Partners. Did you participate using the web or did you attend in person?

Partners is a great program to be associated with. I learned a lot. I also had the pleasure of participating both online and in person. I would definitely recommend Partners to my friends.

What was your favorite part of this experience?

My favorite part of this experience was the interaction with others, meeting most of them in Albany, and hearing their stories in life whether they had the disability or if a family member of theirs have one.

Would you like to share something important that you learned at Partners?

I learned about inclusion which is very important to me because I believe that everyone should be treated the same regardless of whether or not they have a disability.



Tell me a little about yourself.

I am an outgoing person. I love to have fun. I try my



best at everything I do. I believe that everything happens for a reason. I have amazing people in my life who I care so much about.

Do you work or go to school or do both?

I just started working at Arby's not too long ago. I'm really enjoying it so far. I am not attending school, I just graduated from the transition program this past June.

What do you do for fun?

I love to have a good time whenever I get the chance to. I love to go shopping (just not grocery shopping), watch movies with friends and family. And just plain hanging out with people!

Would you like to share a health and wellness tip?

The way I exercise is by walking with friends! It's much more fun that way.

To learn more about New York State Partners in Policymaking, please visit <http://www.nyspip.org/>



Is there an Advocate in the House?

QUESTION: My son's teacher calls me often to come pick him up because he is arguing with another student. I can't always leave work to get him. And I'm worried he is missing so much instruction. He is 10 years old and has an IEP. He is fine at home and does not want to talk about school.



Julie Buick
Parent Education
Specialist



Noran Shiner
Advocate



Julie: Regional Supervisor Kathleen Milliman* suggests that if parents are repeatedly being called to pick up their child with a disability, who is receiving special ed services and has an IEP, then in order to have access to your child's right to due process, and to follow the guidelines for students with behavioral needs, you need to request a letter of suspension. In this way, data is being driven that this child is removed from placement.

Norann: What is happening too, is that parents are being told the child is *not* suspended, and that presents a problem. How do you request that you get a letter of suspension, when the child is not officially suspended? In fact, the child is suspended; if a student is not in school, he is suspended. If this is the case, what I would tell a parent to do is to call a regional associate.

Maria: From a parent perspective, I don't want my child to be suspended... isn't it good if my child is not suspended?

Julie: We look at suspension as a negative, where really, if your child is being suspended and especially if he has an IEP and is receiving services, it could be looked at

as, "there's a need that's not being addressed and we need to look at what other support can we get in place to support this child." What support does the student need to be able to stay in the current placement, benefit from instruction, and have meaningful opportunities in the classroom, rather than in the nurse's office, the principal's office, or at home? We can look at suspension as providing an opportunity to collect data as families and as advocates.

Also, if a child is suspended, that is happening at the building level. Families need to immediately notify the special ed. director or chairperson. An updated functional behavior assessment may be in order. The time to do this is now! Don't wait until annual review time.

Maria: Having a child removed without an official suspension may be used as a strategy to avoid arranging for additional support.

Norann: Well, it's not an effective strategy, because the child learns, "if I misbehave, I get to go home and play games all day."

Julie: Ultimately, it's the child who is impacted the most because it becomes a learned behavior. A child learns that if he does a specific behavior, that's what gets you removed from that environment. Again, I would say this indicates a need in that child. Maybe they are overwhelmed by the learning environment or there's not enough support in place.

Norann: We need to educate families, too, on how suspension is viewed. I'd like to see that changed. We could look at it as a positive, as a great way to lead into what supports and services are needed for the child.

Julie: We are referring to a 10-year-old child in this case, but we also get calls about young adults who have made very significant infractions. Before we get to adulthood where there is no safety net to catch them, let's look at suspension in the younger years as an opportunity, while still in school, to address the challenges and issues that arise in that child. It can be a way to inform everybody on the team that we have an issue here and that we all need to come to the table and work together on behalf of this child.

And there may be barriers to this because suspension always triggers a family to have an emotional reaction to it, that, "my child is bad, he's not good enough; she's not following the rules. But another way to look at it is, "this is good information that we can use, move forward, and figure out what to do next. Sometimes, as parents and as advocates, we get caught up in the issue, and all the stuff that happened, and how horrible it is. So we have to acknowledge what happened, but not dwell on that. The question is, what do we do now, how do we move forward?"

Norann: Sometimes I feel that districts don't know what to do. They are lost. Instead of reaching out to the community, to agencies and resources that can offer support, they feel they need to handle it solely within the district, and that can prolong problems. There's not always a sense of community, of collaborating with other agencies. And yet, in the near future, this change has to happen. OPWDD and ACCES-VR

are requiring it. Hopefully, districts will experience that working with other agencies is a good thing. The Advocacy Center, for example, is being utilized by districts a little more now than in the past.

Julie: We encourage families to report to the regional associate when there is a violation of compliance or in following the process, but parents can be reluctant to take that step. The regional associate is there to help them get positive outcomes and provide information about the special education process and regulations. So parents can call and make an inquiry. The regional associate is part of the team and there to support families.

Norann: Sometimes parents don't know they should be taking that step; they think we advocates should be making the call, when in fact, it is extremely important that the Regional Associates hear directly from parents. Families don't know they have the power to make an inquiry or complaint, whether over the phone or in writing.

Julie: We can put out the fire and help support the family and encourage them to reach out to the Regional Associate, but we can't always do it for them. State Ed is not aware of infractions and can't keep track of trends unless parents report a problem. One really important reason why parents need to get a letter of suspension is that once a student is removed, he or she must receive alternative instruction, such as a tutor. Families may not know this.

Norann: Make your request for a letter of suspension, *in writing*. And don't forget to date your letter.

**Kathleen Milliman is the NYS Education Department, Special Education Quality Assurance Regional Supervisor, Western Regional Office. For a complete listing of NYS Regional Associates, please visit: <http://www.p12.nysed.gov/specialed/contactseqa.htm>*

The Advocacy Center News



Kathy Giordano presented to a Congressional Caucus about Tourette Syndrome on behalf of The Tourette Syndrome Association (TSA) this past fall. Kathy is the TSA's Education Specialist and she coordinates Tourette Advocacy and Support at The Advocacy Center. Kathy was part of a panel that presented testimony. For details, please visit: <http://www.tsa-usa.org/news/0913CongCaucusSep17.html>

◀ *Kathy Giordano delivers testimony.*

Check out our new Coffee Talks!

Enjoy these short videos featuring The Advocacy Center staff discussing topics of interest regarding disabilities. New topics include: **Developing an Attitude of Gratitude** and **Disability Awareness**

DifferentAbility Awareness Day

On November 26, staff and volunteers from The Advocacy Center spent a day at French Road Elementary School in the Brighton Central School District, helping to raise awareness about disabilities to fifth graders. Public Education Coordinator Courtney Dolan encourages students to embrace "different abilities" through fun, hands-on activities and thought-provoking exercises. The day concluded with a dynamic, interactive drum circle and performance.

For more information on Disability Awareness workshops and customized programs, please contact Courtney Dolan at (585) 546-1700 or dolan@advocacycenter.com.

Medical Needs Series Webinar Slated for Spring 2014

The Advocacy Center launched a new medical needs series this fall. *Meeting Children's Medical Needs in the Home, School, and Community* was designed to help parents and professionals navigate the multiple systems of care necessary to serve children who have both disabilities and medical needs.

Meeting Children's Medical Needs will be offered again in the spring of 2014 as a three-part comprehensive webinar series. Public Education Coordinator Courtney Dolan says, "The series has opened the doors for better communication about how to support both families and practitioners in the community. By offering it as a webinar, we will reach even more families and community members. The series is funded by a grant from the New York State Developmental Disabilities Planning Council. For more information, please contact Courtney Dolan, Public Education Coordinator, at (585) 546- 1700 or email: dolan@advocacycenter.com.

How to encourage your child to eat more fruits and vegetables

Try using a visual guide such as *My Plate*. Print and hang on your frig as a reminder or make placemats for your family.

See all the printable resources available at *Choose My Plate*:

<http://choosemyplate.gov/print-materials-ordering/graphic-resources.html>



Tips for building a healthy plate

- Make half your plate fruits and vegetables.
- Switch to skim or 1% milk.
- Make at least half your grains whole.
- Vary your protein food choices.
- Keep your food safe to eat - learn more at www.FoodSafety.gov.

What to do if your child has sensory aversion to the texture of fresh fruits and vegetables??

Some kids (and adults) cannot tolerate the texture of fresh fruits and vegetables in their whole form. Try to change the texture of by:

- Chopping and cooking vegetable into soups such as broccoli soup, squash soup, vegetable soup, tomato soup. Look for recipes that don't have a lot of fat – you don't want to solve one problem and create another!
- Offering combined fruit and veggie juices (that taste primarily like fruit juice)
- Make fruit smoothies – a kid that won't touch strawberries, blueberries, or bananas may be more than happy to if these are well blended with a little yogurt and milk or juice.
- Make applesauce in the crockpot.

Frozen fruits and vegetables are great to have on hand. Canned items are a lifesaver too; just watch for sodium and sugar content.

Health Wellness

14 WEEKS TO A HEALTHIER YOU

A **free**, personalized, web-based physical activity and nutrition program. Offered by the National Center on Health, Physical Activity, and Disability Exercise, track your eating, and be inspired to be healthy right at home:

What is the program?

- Description: A **free**, personalized, web-based physical activity and nutrition program
- Target Audience: People with mobility limitations, chronic health conditions and physical disabilities
- Goal: To help you get moving and making healthy nutrition choices
- Duration: 14 weeks

How does it work?

- You register for the program and tell us a little about yourself.
- We take the information you gave us and, to the best of our abilities, provide you with personalized resources and exercises that meet your individual needs over the course of 14 weeks.
- Because there is new material each week that builds on the previous weeks, the program works best if you visit at least once a week.

What do I get throughout the program?

- New, personalized weekly exercises
- Physical activity and nutrition tips
- Motivational resources
- Weekly recipes
- Features to help you track your activity and what you eat
- Optional reminders and alerts
- Opportunities to connect with other participants
- Access to 14-Week coaches

To learn more or to register, please see <http://www.ncpad.org/14weeks/>

Health Consequences of Overweight and Obesity

Overweight and obesity increases the risk of a number of other conditions, including:

- Coronary heart disease
- Type 2 diabetes
- Cancers (endometrial, breast, and colon)
- High blood pressure
- Lipid disorders (for example, high total cholesterol or high levels of triglycerides)
- Stroke
- Liver and gallbladder disease
- Sleep apnea and respiratory problems
- Osteoarthritis (a degeneration of cartilage and its underlying bone within a joint)
- Gynecological problems (abnormal periods, infertility)

“The benefits of physical activity are universal for all children, including those with disabilities.”



Out and About - Stay Active this Winter



SportsNet Wheelchair Basketball Try It Clinic

January 28, 2013, 5:30 - 8:00PM

For anyone who is interested in learning about wheelchair basketball. 1000 Elmwood Avenue, Gym at Door #1

Cost is \$2.00 at the door

Contact us by Wed., January 23!

Call or send email with Name, Contact Info, and Number of People attending to:

Anita O'Brien, SportsNet Manager, 585.271.1894, ext. 1742, aobrien@rochesterrehab.org
HOSTED BY the Monday Night Recreational Basketball group and the Rochester Wheels team.

SportsNet is an inclusive sports and recreation program of Rochester Rehabilitation.

CP Rochester Shared Ski Adventures January 12 – March 9



is an ADAPTIVE Learn to Ski Program that helps people with disabilities become independent skiers. We ski at Swain Ski Resort in Western New York. For further information or to register, please contact Shared Ski Adventures (SSA) Coordinator Nicole Fulle at CP Rochester Office, (585) 295-1587 ext. 2282 Cell: (585) 749-9333 or email: nfulle@cprochester.org or Sean Ossont at (585) 704-5740; email: sean_ossont@hotmail.co

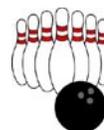
Look for CP Rochester's current recreation offerings at: <http://www.cprochester.org/recreation.asp> or call the Recreation Program at 585-295-587 x2282

CDS Monarch

offers a variety of evening and weekend classes that promote health and wellness for people of all ages and

abilities. The water is always warm at CDS's temperature regulated pool. For current offerings, please visit <http://www.cdsmonarch.org/> or phone the main office at (585) 341-4600.

Webster SEPTA Sports Bowling



January-March at Empire Lanes in Webster, NY on Sunday afternoons. Webster Special Education Parent Teacher Association SEPTA sponsors sports programs for children with special needs-ages 5-21.
Contact: Larry Ritzenthaler at (585) 872-3098 for further information.

Pieters Family Life Center Water walking and aquatic classes

Check out the HydroWorx 2000 therapy and fitness pool, a fully accessible pool that has an underwater treadmill which allows for low-impact therapeutic exercise and aggressive conditioning for serious athletes.

The Pieters Family Life Center also includes a fitness center, universally designed to meet the need of seniors, wheelchair users, individuals with physical and intellectual disabilities as well as athletes and exercisers.
<https://www.pietersfamilylifecenter.org/Default.aspx?RD=1355>



Family Swim at Holy Childhood for AutismUp members

Family Swim takes place from 1-3pm on one Sunday per month at Holy Childhood, 100 Groton Parkway, Rochester, NY 14623

This program is FREE for AutismUp members. For more information, please contact Rachel Rosner, AutismUp, (585)248-9011, rrosner@autismup.org

Therapeutic Horseback Riding at Heritage Christian Stables

Operated by Heritage Christian Services, PO Box 200, Webster, NY 14580
(585) 872-2540.

For further information, see www.heritagechristianstables.org



Equicenter Therapeutic Riding and Non-riding Program Options

For more information, please contact: Lindsay Alberts, (585) 624-7777
lalberts@equicenterny.org
Location: 3247 Rush Mendon Rd. Honeoye Falls, NY 14472

JCC Rochester

offers a variety of fitness and aquatic programs. The Jewish Community Center of Greater Rochester, 1200 Edgewood Avenue, Rochester, NY 14618
For more information, call (585) 461-2000 or see <http://www.jccrochester.org/about-the-jcc/col/fitness-center>

When Your Child Refuses To Go To School

School avoidance syndrome is one of the most common causes of vague, unverifiable symptoms in school-age children. This syndrome may be triggered by stress.

How does a parent distinguish between a real illness and anxiety? Ask yourself the following questions:

Does the child have a fever? Was he or she vomiting? Did the child have diarrhea? What was his or her condition the night before? Does your child complain of feeling sick only on school days and then seem fine on weekends?

If no physical factors are involved, and this has happened several times before, consult your child's doctor to rule out a medical problem.

It's also important to ask the child about what's happening at school. The American Academy of Pediatrics (AAP) stresses that children may have a difficult time explaining what worries them.

The AAP and American Academy of Family Physicians (AAFP) identify the following situations as school avoidance triggers:

- Teasing by other children, such as being called "ugly" or "fat"
- Fear of failure
- Threats of physical harm from a school bully
- Actual physical harm
- Anxiety over using a public bathroom
- Major changes at home, such as a divorce, death of a family member or pet, moving to a new home

The AAP stresses that the first step in managing school avoidance is to have the child checked by a doctor so that actual physical problems are ruled out. Vision and hearing problems, for example, may cause high levels of school-related anxiety for a child. If no physical problems are found, the doctor can help you understand the child's anxiety and develop a plan to get the child back to school.

~ From the University of Rochester Medical Center
<http://www.urmc.rochester.edu/encyclopedia/content.aspx?ContentTypeID=1&ContentID=987>

Mental Health/Social/Emotional Wellness

<http://www.cmhcwny.org/home.html>

Children's Mental Health of Coalition of Western New York

A voice for families of children with emotional, social, behavioral, developmental, and learning challenges.



Serving: Allegany, Cattaraugus, Chautauqua, Chemung, Erie, Genesee, Livingston, Monroe, Niagara, Ontario, Orleans, Schuyler, Seneca, Steuben, Tioga, Tompkins, Wayne, Wyoming and Yates Counties

Dad's Corner

By Patrick Connelly



Patrick and Sean Connelly

Being Sean's dad has taught me more about joy, love and patience than I could ever have imagined. It has also put us in contact with incredibly phenomenal people. We have been blessed to have had extraordinary teachers and therapists throughout his schooling at Creekeside, wonderfully caring staff at Holy Childhood and countless numbers of exceptional coaches, volunteers and buddies. Rochester IceCats, Webster Challenger Baseball, TIES drumming, CP Rochester Bowling, Special Olympic events and FCDSN events are just a few of the activities that have enhanced our lives and forged friendships with some of the finest people on the planet!

Check out this blog by Rob Rummel-Hudson:
<http://www.schuylersmonsterblog.com/>

Fighting Monsters with Rubber Swords

As parents, we're probably almost certainly unprepared for the disabilities of our children, at least at first. We go into battle against monsters without so much as a BB gun in our hands. What we discover as we go is that sometimes, we don't need weapons. We simply need different tools, such as patience, and tougher skins, and ingenuity. And most of all, we need to learn forgiveness, primarily for ourselves.

Resources on Health & Wellness



The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities, Office of the Surgeon General (US); Office on Disability (US), Rockville (MD); Office of the Surgeon General (US); 2005.
<http://www.ncbi.nlm.nih.gov/books/NBK44667/>

National Down Syndrome Society website – see the section on Wellness.
<https://www.ndss.org/Resources/Wellness/>

UCP – United Cerebral Palsy website
<http://ucp.org/resources/health-and-wellness/wellness/>



Are you Ready?

Make your experience count as you learn to make an even bigger impact in the lives of people with diverse needs.

The Warner School of Education will prepare you to work with students and clients in school, community and counseling settings. Consider these exciting options:

- Special and Inclusive Education Teacher Certification
- Annotation to Teach Students with Severe and/or Multiple Disabilities
- Specialization in Applied Behavior Analysis
- Master's Degree in Human Development with a Specialization in Developmental Differences

Generous grants and scholarships are available to qualified applicants.

The Warner School offers graduate programs in:

- Teaching
- Counseling
- Human Development
- Higher Education
- Educational Policy
- School Leadership
- Health Professions Education



WARNER
 SCHOOL OF EDUCATION
 UNIVERSITY OF ROCHESTER

www.warner.rochester.edu • admissions@warner.rochester.edu • 585.275.3950

From the Editor



It was Friday. For every item I scratched off my to-do list, two more easily replaced it. Exercise was at the bottom of the list, an unwise choice.

Sometimes my kids motivate me to do the right thing. Nick showered and had breakfast and was sitting on the recliner watching TV. Nick is 21 years old, 5 feet tall, and likes to eat; except for the age part, we are a lot alike. "Hey Nick, wanna go to the Y?"

A little while later, we hopped on treadmills side by side. After twenty minutes, Nick stopped. I was surprised and wondered why he didn't have the energy to continue. Where was he going? My worry machine cranked up... here we go... does he have a thyroid problem? Is he bored? Is he depressed? Is he hurt? Is he giving up? Is...." He then stepped up onto an elliptical and then really started working hard – for another thirty minutes. He proudly stepped down, exclaimed "Whew!" and smiled.

Worry machine off for the moment.

HAPPY HOLIDAYS

Wishing all of our families and friends a peaceful and joyful 2014.

Maria Schaertel



**THE
ADVOCACY CENTER**
Putting People First

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

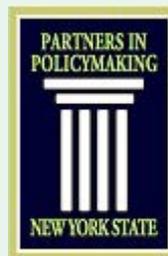
Non-Profit
US POSTAGE
PAID
Rochester, NY
Permit No. 139

Partners In Policymaking News

Time to Register for Partners in Policymaking 2014

Partners in Policymaking is an innovative leadership training opportunity for self-advocates and parents/family members of individuals with developmental disabilities. Expand your personal advocacy skills to develop a more global perspective.

- Participate in an online community learning about disability history and current advocacy issues
- Attend one large group in-person statewide session and one small group regional session
- Develop partnerships with legislators and policymakers
- Become a public figure committed to positive system change



For more information, please visit www.nyspip.org or contact

The Advocacy Center, Jackie Yingling, Training Coordinator.
Email: yingling@advocacycenter.com • phone: (585) 546-1700 ext. 224

To apply, click here: http://www.nyspip.org/class_application.cfm

This newsletter is published by
The Advocacy Center
590 South Avenue Rochester, NY 14620
(585) 546-1700 1-800-650-4967
www.advocacycenter.com

Funding is partially provided by a Family Support Services Grant by the OPWDD (Office for People With Developmental Disabilities) and by the U.S. Department of Education, Office of Special Education and Rehabilitative Services.

Publication within this journal of articles and information should not be considered an endorsement by The Advocacy Center and/or the funders.

EDITOR: Maria Schaertel
INTERIM EXEC. DIRECTOR: Allyn Stelljes
DESIGN & PRINT: Sarah Stein

This issue underwritten by



James C. Traylor, ChFC, ChSNC
Special Care Planner, Financial Services Professional
http://financialarchitectsupstate.com/james_traylor