The Advocacy Center Has Moved!

The Advocacy Center and LDA Life and Learning Services are now co-located at 1650 South Avenue, on the Wolk Campus of the Al Sigl Community of Agencies. Our two agencies became formally affiliated in early 2014, and we are still working toward merging to form one organization. LDA has been located on the second floor of this building for several years, and our agencies will now be occupying a wing of the first floor as well.

The reception area for both The Advocacy Center and LDA is on the first floor. All visitors are asked to sign in at the reception desk. The address for The Advocacy Center and LDA Life and Learning Services is: 1650 South Avenue, Suite 200, Rochester, NY 14620.

Our main phone number remains (585) 546-1700; LDA's primary phone number - (585) 263-3323 - still works. The direct phone numbers for LDA staff and the on-call numbers for LDA programs still work, as well. Our phones are open from 8am-5pm; our office hours are 9am-5pm.

We are very excited about our new Training Center here at 1650 South Avenue, a state-of-the-art space that allows for larger audiences for our trainings for individuals, family members, and professional partners. We hope you will be joining us at one of the many trainings we offer year-round. Check out our website to view our upcoming offerings.

Once the merger is finalized, we will be excited to share with you a new name and logo for our organization. We are looking forward to exploring ways to combine our strengths to better support individuals with disabilities, their families, and the community.

In the meantime, our programs continue to operate as before, and our top priority continues to be providing high quality services and supports to meet the needs of individuals with disabilities and their families.

Allyn Stelljes
Colin Garwood

For current news on the merger of The Advocacy Center and LDA Life and Learning Services, please visit our website: http://advocacycenter.com/news-about-the-merger
With some planning, support, and resources, your child with a disability and diabetes can have a great camp experience. Allison Pitkin, Manager of Mission Delivery at the American Diabetes Association, has tips for parents of children with diabetes who are looking to enroll their child in a summer camp.

When applying for any camp, Allison suggests you reach out and work directly with the camp coordinator to make sure your child is able to stay safe and manage his or her diabetes while at camp. Here are some ways to facilitate the conversation:

- Ask if there is a camp nurse, if he or she is knowledgeable about diabetes, and what accommodations will be available in the event your child may need assistance.
- Prepare a supply box with extra supplies such as quick sugar snacks, and blood glucose/ketone testing supplies.
- Discuss when you want the medical staff to call you. Some camps discourage parents from calling camp. Let them know under what circumstances you should be called.
- Prepare a plan for the camp nurse about blood glucose monitoring and glucagon administration.
- Put all information the camp staff needs about your child’s diabetes in writing.
- Go over all information at check-in.

The Rochester office of the American Diabetes Association partners with Rochester Rotary Sunshine Campus to serve campers with disabilities. Campers with disabilities and diabetes may also be accommodated at Camp Aspire, depending upon each camper’s needs. Camp Aspire is designed specifically for campers with diabetes.

Camp Aspire tries to accommodate all kids that have diabetes. Should a camper require 1-to-1 assistance at camp, our partners at the Rochester Rotary Sunshine Campus operate a summer camp for children with disabilities that provides extra support that may be needed for children with diabetes and a developmental disability that severely impacts motor/learning skills. This camp is free to campers that qualify. For more information, email Brandi Koch at brandi@rochesterrotary.org or 585.546.7435 x210, or visit http://sunshinecampus.org.

The American Diabetes Association has a free CD module on the basics of diabetes management for counselors and camp coordinators. Please contact Allison Pitkin for your free cd at (585) 458-3040, ext. 3472 or email Apitkin@diabetes.org

Q. My daughter has a developmental disability and diabetes as well. She wants to go to summer camp, but I am concerned about her ability to manage her medicine.
Lunch and Learn

Bring your lunch and learn the basics of special education in these one-hour workshops, from noon to 1:00 pm on the dates listed, at The Advocacy Center, 1650 South Avenue, Suite 200, Rochester, NY 14620

Tuesdays, April 7 OR April 21, 2015 - CSE Overview
Thursday, April 9, 2015 - Continuum of Services: Special Education Placement
Tuesdays, April 14 OR April 28, 2015 - IEP Essentials
Thursday, April 16, 2015 - RTI, 504 & IEP: What’s It All About?

Register is required. Workshops are FREE to family members. Register online via our calendar at www.advocacycenter.com or by phone at 585-224-7399.
Please request any special accommodations at least two weeks before workshop.

CREATING A LIFE AFTER HIGH SCHOOL

Mondays, April 13, 20, 27, May 4 & 11; 5:00pm-8:00pm
Dinner is provided.
The Advocacy Center, 1650 South Avenue, Suite 200, Rochester, NY 14620

A free, five-session program designed to help answer the many questions students and family members have as they enter the adult world:
• Where will I live?
• Are there opportunities for learning?
• Where will I work?
• What will I do for fun?
• What agencies can help to provide support?

The individuality of each student is valued and encouraged throughout all sessions.

Registration is open to all students in Monroe County NY, ages 15-21, who are living at home and who have established DDRO eligibility. A parent/guardian or other family member must accompany the student to all sessions.

REGISTRATION IS REQUIRED BY 4/13/15. To register, contact Carrie Burkin by email, burkin@advocacycenter.com, or by phone at (585) 224-7331.

At the end of this program, funds are available to each student to apply towards a future vision. Please note: participants must attend all sessions to be eligible to receive funds.

Please request any special accommodations at least 2 weeks before first session.

In Collaboration with Self-Advocacy Association of NYS, Holy Childhood, Monroe 2-Orleans BOCES

OPWDD Region 1
Family Support Services
Collaborative Planning and Advocacy Forums
Make your voice count!

We need your help and input on what services are needed in your communities.

Individuals living with family, family members and agency representatives are invited to attend.
Light dinner will be provided.

FSS Advisory Council of Monroe County:
Thursday, April 30, 2015, 6-8 pm
3399 Winton Road South,
Rochester, NY 14623
(CP Rochester Multi-purpose Room)
If attending, please RSVP by phone or email by April 24.

FSS Advisory Council of Ontario, Wayne, Seneca, and Yates Counties:
Thursday, May 7, 2015, 5-7 pm
3071 County Complex Drive
Canandaigua, NY 14424
(Ontario ARC Conference Room)
If attending, please RSVP by phone or email by May 4.

Email: region1fss@opwdd.ny.gov
Phone: (585) 461-8726 or (585) 461-8830.
Supporting Behavioral Needs of Individuals with Neurological Differences -
Half-day Conference in Batavia, NY
April 24, 2015, 9:00am-12:00 pm
Genesee Arc Community Center Forum Room, 38 Woodrow Road, Batavia, NY 14020

This conference will explore the nature of a child’s behavior and help to determine when a positive behavior plan is appropriate. Presenters will discuss the essential elements of a positive behavior plan. Participants will learn positive interventions and strategies to support students with challenging behaviors in affirming and constructive ways.

FEATURED PRESENTER:
Kathy Giordano, international speaker and education specialist with the National Tourette Syndrome Association. Her book “A Family’s Quest for Rhythm” will be available to purchase after this workshop.

Continental breakfast will be provided.

REGISTRATION IS REQUIRED BY 4/7/15. Please register on our website at www.advocacycenter.com or phone (585) 224-7399.

PARENTS OR CAREGIVERS, registration is FREE.

PROFESSIONALS, cost is $10.

Thumbs Up!

Miracle Field & Ron Kampff
By Maria Schaertel

Teamwork Makes the Dream Work. The slogan for a recent fundraising event sums up Ron Kampff’s approach to creating a new adaptive sports field in Webster. By teaming up with fellow coaches, players, parents, businesses, government, and community members, Coach Ron is raising money and building support for Miracle Field.

In 2001, Kampff founded Webster Challenger Little League Baseball for children with disabilities. Even with cooperation and support from the Webster Athletic Association, Ron has sometimes struggled to find open baseball fields for the ever growing number of children and young adults from all over the Rochester area who want to play. Miracle Field is his solution.

“Our goal is to build an adaptive field for a variety of sports and recreation activities that includes people with developmental and physical challenges.”

A testament to Kampff’s commitment to the players, many of the kids who first participated in Webster Challenger Baseball are now young adults whose affection for Ron has grown through the years, along with their baseball skills and enjoyment of the sport. With over 80 participants, teams are now divided among younger children, and teens and young adults.

The field will not be limited to Webster Challenger participants or to baseball. Over 400 greater Rochester area Challenger participants will have the opportunity to use the field as well through their teams. The field will accommodate other sports as well.

Want to learn more or support the development of Miracle Field? Please contact Ron Kampff by phone: (585) 737-7499 or email: ronkamp40@yahoo.com.

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SPORTS AND RECREATION

This section provides only a sampling of the many opportunities available for children and adults to go out and have some fun, get some fresh air, learn a skill, explore the arts, socialize, and be a part of a community.

Together Including Every Student (TIES)

promotes the participation of students and young adults with developmental disabilities in extracurricular and community activities.

TIES also sponsors some group recreational activities, such as drumming circles, cooking classes and outrigger canoeing. For information on current activities, please contact Kathy Costello at (585) 546-1700, 1-800-650-4967 (toll free in NYS) or costello@advocacycenter.com.

SportsNet

An adaptive sports and inclusive recreation program of Rochester Rehabilitation.

Sports include: adaptive cycling, aquatic exercise, golf, outrigger canoeing, power wheelchair soccer, sailing, sled hockey, stay fit, wheelchair basketball, Rochester Wheels (adult wheelchair basketball team), Rochester Rookies Junior Wheelchair and Ambulatory Sports, and wheelchair fencing.

For more information, please contact: Anita O’Brien, SportsNet Manager at (585) 271-1894 ext. 1742 or aobrien@rochesterrehab.org. Visit the website at http://www.rochesterrehab.org/services/sportsnet/

Dazzle

Dazzle School of Visual & Performing Arts, 110-112 Webster Avenue, Rochester, NY 14609,

Dance, music, drama, visual art, fashion design, and script writing, classes for higher education

Website: www.dazzleschool.org

Phone: (585) 288-0050 or email: mail@dazzleschool.org

Spectrum Creative Arts

3300 Monroe Ave., Rochester, NY 14618

Offers music therapy, art therapy, music instruction, and art instruction

http://www.spectrumcreativearts.org/

Phone: (585) 383-1999 or toll free (855) 444-0201

Email: office@spectrumcreativearts.org

Rubies

Core Athletix, 1344 University Ave.

Suite #5000, Rochester, NY 14607

An inclusive cheer team, coordinated by Core Athletix. Practices are Sundays from 1.00 to 2.00 pm. Participation in Rubies is free of charge. Contact: Core Athletix, (585) 244-2496 or visit www.coreathletix.com. Click on All Stars to find the Rubies page.

The Rochester Rookies

For children and young adults with physical disabilities, ages 2-21, that are interested in a fun, competitive and recreational sports program that participates in local, regional, national and international levels of competition.

Jo Ann Armstrong. Phone: (585) 393-7182

Email: RochesterRookies@gmail.com

Adaptive lacrosse program for kids grades K-12. For information, please call or text Julie Boglione at 585-750-8677 or email jboglione@gmail.com. Visit the website: http://breakingbarrierslacrosse.leagueapps.com/camps

Webster Sports Opportunities

For children and young adults with disabilities. Sports offerings followed by contact information:

Challenger Baseball at Ridge Park, Town of Webster - Ron Kampff at ronkamp40@yahoo.com or (585) 737-7499

Basketball at the Bayview YMCA - Maureen Preston at (585) 336-9921; mmpreston@gmail.com

Flag Football and Soccer at the Bayview YMCA – Linda Burke at lindyb911@yahoo.com

Bowling at Empire Lanes – Larry Ritzhenthaler at larryritz@yahoo.com

Western New York Challenger Sports League

Locations include Clarence, Gasport, Lockport, Medina, Middleport, and Newfane. http://wnychallengersports.com/home/

Sports offerings followed by contact information:

Baseball, Mark (716) 696-2463 or Vince (716) 439-9600

Basketball, Jen (716) 735-7987; Vince (716) 439-9600; Mark (716) 696-2463

Bowling, Medina Lanes – Cheryl Naish (716) 795-3056 or Zimmy (716) 696-2463; Allie Brandt and Brad Angelo Lanes – Laurie George (716) 433-6867 or Linda Conlin (716) 433-4845

Golf, Jim Benoit (716) 795-3433

Volleyball, Jen (716) 735-7987, Vince (716) 439-9600, Mark (716) 696-2463
Sports and Recreation continued

Therapeutic Horseback Riding at Heritage Christian Stables
1103 Salt Road in Webster, NY
Upcoming sessions:
Spring, April 27 – June 27
Summer, July 6 – Aug. 29
For information, please call (585) 872-2540 or email Lorrie Renker: lrenker@heritagechristianservices.org

Never Say Never Foundation
Never Say Never Stables, 906 Maple Drive, Webster, NY 14580
Provides equine (horse) assisted activities and educational experiences to children of all abilities through services and programs, such as camps, educational field trips, and special events. Equine assisted activities sessions are made by appointment.
Please visit the website for further information http://www.nsnstables.org/default.html

Rochester Area YMCA
The Y offers a variety of camp experiences at many locations: City of Rochester, Westside, Eastside, Finger Lakes, and Adirondacks.
For further information please visit the website http://rochesterymca.org/programs/camps or phone (585) 546-5500.

Fully Accessible Treehouse at Rochester Rotary Sunshine Campus
Featuring wheelchair-accessible ramps, wide platforms, sensory equipment for enhanced learning, a cabin enclosure and tree-top views for campers.
Expected Grand Opening July 2015!
For more information, please visit: http://www.sunshinecraftus.org/SunshineCampusTREEHOUSE.aspx

Cobblestone Arts Center
1622 Route 332, Farmington, New York 14425
Day Habilitation includes experiences in Music, Dance, Theater, Visual Arts, Public Speaking, and Media Studies.
For more information, email cobblestoneartscenter@gmail.com or phone (585) 398-0220 or visit http://cobblestoneartscenter.com

ROC Your Flight
The Arc of Monroe County, Greater Rochester International Airport, and TSA (Transportation Security Administration) offer ROC Your Flight. This program is designed for any person who has a disability, wants to fly and would like to gain experience with the process. This program gives individuals with disabilities and their families the opportunity to go through a training at the airport where participants are acquainted with the security process, navigating the airport, and boarding a plane.

Training sessions: Saturday, May 16, 2015 and Saturday, October 17, 2015
All sessions begin at 4:30 pm and run approximately 2 hours. Contact Jaime Dermody at (585) 271-0660, ext. 2037, for further information.

After working for three years in the travel industry, Nicole Thibault decided to open her own agency, combining her professional travel knowledge with her experience parenting two children with disabilities. Magical Storybook Travels offers families assistance in vacation planning that accommodates a family’s particular needs. “I found that because of my personal experience with my boys, I was in a unique position to assist families with special needs plan their vacations.” Nicole’s services include an interview to determine a family’s needs, creation of social stories and picture schedules to prepare for vacation, creation and booking of a vacation package, recommendations of activities based on sensory issues, assistance with daily itinerary planning, restaurant recommendations based on special diets, and a review of travel documents prior to departure.

For those out of the Rochester area, a meeting can be arranged via phone, Skype or Face Time. Contact Nicole by phone at (585) 800-6951 or email Nicole@magicalstorybooktravels.com and visit the website: http://www.magicalstorybooktravels.com
Featuring Chris Tumminelli, past president, Flower City Down Syndrome Network, Founder of local D.A.D.S (Dads Appreciating Down Syndrome) group, and father of son, Landon.

How old is Landon? What does he like to do? Landon is a 7-year old boy who loves everything that any little boy does. Baseball, dance class, bowling, swimming, playing with his car collection...you name it, he likes it. Landon really likes music, and he can dance much better than dad, of course. He gets his dance moves from his mom for sure.

What is your relationship like with Landon? Has he changed your outlook on life? Landon and I are extremely close. He is everything in my life and my #1 priority. Landon has shown me aspects in life that you cannot learn through any other medium. He teaches me patience, overcoming challenges, and most importantly, how to love and become a better person.

What motivated you to create a D.A.D.S. chapter? I attended a National Down Syndrome Conference in 2010 and sat in at a workshop on how to start a D.A.D.S. (Dads Appreciating Down Syndrome) chapter. We brought the core values back to Rochester and pitched the idea to our Board of Directors of Flower City Down Syndrome Network. With the help of some other local fathers, it steamrolled into its current form. After many years of helping run the D.A.D.S. chapter, I passed the baton to another father who now runs the local D.A.D.S. chapter.

How does a dad join the group? Any father who has a child with Down syndrome can contact us by phone: (585) 237-8921, email: info@dadsroc.com, or visit our website: www.dadsroc.com. The D.A.D.S. meetings are always open to all fathers and no need to sign up, just show up.

How has the FCDSN supported you and your family? FCDSN has the best resources for families in the Rochester area who have a relative with Down syndrome. For over 23 years, FCDSN has been reaching out and embracing families to help us all along the journey of life. The most important benefit I think is the social aspect of meeting other families in Rochester. The connections we have made over the years have created an extended family of friends for life. The word “NETWORK” in FCDSN really defines what they do. It is that togetherness of families that help us all.

Anything else you want to share with our readers? In life we are all faced with challenges. Always look at the bright side of the challenge and you will see that having a child with Down syndrome or any disability can truly be a blessing.

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What is Service Coordination and how can it help my child?

Service Coordination assists individuals with developmental disabilities and their families in accessing supports and services in the community, according to their needs. Service coordinators work in partnership with individuals and families to develop, implement, and maintain a plan to access supports and services.

A Service Coordinator may help you in any number of ways such as: apply for benefits, help you negotiate social service agencies, explore programs to make your home more accessible, explore transportation options, explore living options, advocate for your child at meetings or the doctor’s office, and apply for family reimbursement money.

Who is eligible to receive service coordination?

The individual must be deemed eligible by New York State’s Office for People With Developmental Disabilities. The individual must:

• Have a documented diagnosis of a developmental disability
• Demonstrate a need for ongoing service coordination
• Freely choose to receive the service
• Meet financial eligibility.

Prior to accessing services all individuals and families must participate in a “Front Door Session.”

For more information about the Front Door, please call:

Region 1 - Finger Lakes
855-OPWDDFL (679-3335)
Region 1 - Western
800-487-6310
or visit the website: http://www.opwdd.ny.gov/welcome-front-door/home.

For further information about Service Coordination, please phone The Advocacy Center at (585) 546-1700 or 1-800-650-4967 (Toll free in NYS).
The 2015 Spring Session of NYS Partners in Policymaking is in full swing! The class recently met for their one in-person session in Albany, where they created vision boards and had thought-provoking and rousing discussions with presenter Al Condeluci. Members of the class have been meeting in weekly webinars and working online since Feb. 5th when this session began. NYS Partners meets primarily online for a four month period, studying topics of disability history, policy, building community, inclusion, person-centered planning, legislative advocacy, and leadership. Check it out at www.nyspip.org.