AN EVENING OF ART AND JAZZ

By Maria Schaertel

The Advocacy Center’s 6th annual major fundraising event was held June 4, 2011 at George Eastman House, a National Historic Landmark providing an exciting backdrop to the event.

Jazz artists Wycliffe Gordon, Jimmie Highsmith Jr., Bobby Floyd, Annie Wells, Chad O’Brien, Alex Lacquement, and Wills McKenna delighted guests with a variety of performances. In addition, guests were treated to a wide array of activities including the opportunity to bid on art work by local artists featured in the silent auction; stroll through the gardens; attend guided mansion tours; view gallery exhibits; and participate in a live auction featuring club passes to the Jazz Fest and tickets to a Yankees/Red Sox game complete with hotel accommodations.

13WHAM-TV news anchor Evan Dawson welcomed guests to The Advocacy Center Community Awards ceremony. NYS Assemblyman Mark Johns was on hand to present a Certificate of Merit to award winners, recognizing their contributions to our community. The Corporate Support Award was presented to Faraci Lange Attorneys with Matt Belanger accepting the award. Darryl Porter, a member of the City of Rochester Cabinet and Senior Management Team, attended the ceremony as well to congratulate the award recipients.

Paul Shew, Executive Director of The Advocacy Center, reports a 13% increase in revenue from the event over 2010. Mr. Shew credits the increase to the generosity of Presenting Sponsor MVP Healthcare, over 30 other corporate sponsors, advertisers and well-wishers, in-kind donors, and the hard work of staff, board and volunteers.
Jutta Pearl is the recipient of the Barbara Bryson Award, presented to a parent of an individual with a disability who has exhibited pioneering efforts on behalf of individuals with disabilities and their families. For 23 years, Jutta has been a loving parent and strong advocate for her daughter with a disability. Through Jutta's efforts, her daughter has grown in confidence and in the ability to advocate for herself. Jutta taught her daughter that she plays a vital role both in her family and in the community. Jutta extended her experience, knowledge, and understanding of persons with disabilities beyond her own family and out into the community. She is a staff member at Sanford Individualized Residential Alternative at Livingston-Wyoming ARC where she provides care and support to residents. Jutta is the “go to” person when residents want someone to talk to one-on-one. Jutta was nominated by co-worker Ashley Hendershot.

Keith Perlet received the Self Advocacy Award, presented to an individual with a disability who leads the direction of his or her daily life through advocacy and personal choice. Keith graduated in June 2007 from the Rush Henrietta School District. Keith decided to pursue an additional educational credential to further his career possibilities. His goal was to work in the field of Culinary Arts. Keith discovered that the Test of Adult Basic Education would help him get into a certificate program for Culinary Arts. Keith was determined to pass this test, devoting 6 hours per day, 5 days per week, to studying. With perseverance and hard work, he passed the test in 2009 and was accepted into the Rochester Educational Opportunity Center Culinary Arts Program. In May 2011 Keith completed the program and achieved a Culinary Arts certificate. Medicaid Service Coordinator, Cheri Greenauer, nominated Keith.

The Jeanne Krautwurst Award, which recognizes a parent or family member of an individual with a disability who has worked tirelessly to improve the quality of life for his or her family member, was presented to Laura Khederian. Laura worked with her son, Jimmy, for 4 years to make his career dream come true: to work at the Seneca Park Zoo. Through participation in the zoo’s teen program and then volunteering arranged with West Irondequoit High School, Jimmy gained valuable zoo experience as well as increased responsibilities over the past 2 years. Laura always emphasized Jimmy’s capabilities, loyalty, and success. Through Laura’s persistent efforts and spirit of collaboration and Jimmy’s excellent work ethic, everything has come together for him: the zoo staff has agreed to increase Jimmy’s hours to full time. Laura was nominated by Cheri Greenauer, Medicaid Service Coordinator: “We need people like her who see a challenge and never give up.”
Diane Sturmer is the recipient of the Community Inclusion Award, presented to an individual or group whose actions have led to the successful inclusion of individuals with disabilities and their families in their communities. Diane is a Spiritual Life Coordinator for Heritage Christian Services. For the last four years, Diane has guided a team including individuals with disabilities, along with members of a global outreach based in Rochester whose mission is to support people in remote places accessible only by mountain climbing, Climbing For Christ. Through this partnership, individuals with disabilities have the opportunity to participate in the physical and emotional challenges of mountain climbing, as well as make friends along the journey. Diane also created Heart of Dance, a dance troupe consisting of individuals with and without disabilities. Diane has worked for Heritage Christian Services since 1987. Co-worker, Kara Lippa, nominated Diane: “Diane takes the time to share her many years of experience and knowledge with new staff so that we can support individuals in living fully integrated lives.”

Joshua Fidler was presented with the Student Award, which recognizes a student whose efforts have made a positive impact on the lives of individuals with disabilities. Joshua is a TIES volunteer in Brockport. TIES, which stands for Together Including Every Student, is a collaborative effort of The Advocacy Center and area school districts. TIES volunteers are teenagers who support students with disabilities in community activities. As a TIES volunteer, Joshua began supporting a drum circle participant 5 years ago, and he still continues today. Joshua’s Eagle Scout project earned him Eagle Scout Project of the year. He decided for his project not to just create a garden for BOCES 2 students, but to create a garden with the students. He planted seeds with the students and talked about the growing cycle and basic horticulture. Joshua maintained the garden all summer right through harvest. He repeated the same project the following year. TIES coordinator Lisa Mahoney, nominated Joshua: “Joshua is a gift, not only to individuals with disabilities, but to the entire community.”

John Campolieto is the recipient of the Education Award, presented to a devoted individual in the field of education who, through extraordinary efforts, has provided for the educational needs of students with disabilities. John has been an educator for over 4 decades. He began his career as a Special Education teacher at Monroe #1 BOCES then later served as a Vice Principal and Assistant Superintendent. John collaborates with The Advocacy Center to provide teacher candidates at Roberts Wesleyan the unique opportunity to work with parents of children with disabilities. Over the past 4 years, John has helped shape 120 future teachers, helping them understand the value of positive relationships with parents. His roles as teacher and administrator have given him the ability to reach and change the lives of many children with disabilities along with their families. Jeanne Ricigliano, Parent Partner at Monroe #1 BOCES, nominated John and says of him: “John is an innovative ‘mover and shaker’ in the world of education, supporting and creating opportunities that change lives…I am honored to know him.”

Upcoming Workshop

Vicarious Trauma
The Cost of Caring

Presented by Dr. JoAnn Jankoski, EdD, MSW, MS
August 2, 2011 - 8:45 AM to 12:00 PM

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.

Fee: $39 for a single registration; $175 for a group of five ($35 each)
To register and pay online, locate this event on our website calendar: www.advocacycenter.com/calendar.php
Questions?
Call 585-546-1700 ext. 399 or email registration@advocacycenter.com

Dr. Jo, Assistant Professor
Health and Human Development,
Penn State University,
Fayette Campus

Highly recommended for anyone in a caring profession!

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2011 Community Award Winners

Scott Sargeant and guest

The Community Impact Award, presented to a company or organization which promotes opportunities for individuals with disabilities, was presented to Scott Sargeant, Manager of Starbucks Coffee at Twelve Corners in Brighton. Five years ago, Ellen Beisheim, an 8th grade student with a disability, approached Starbucks for a job shadow opportunity. This past school year, Ellen attended SUNY Geneseo’s LIVES program for students with disabilities. Through her hard work and Scott’s influence, she continues to work at Starbucks and is a respected member of the Starbucks family. Scott was happy to accommodate Ellen’s new college schedule. Sarah and John Beisheim, parents of Ellen, nominated by Scott: “Scott’s attitude and actions have done so much to support Ellen’s development of valuable skills in an environment that makes her feel valued and comfortable… In giving Ellen this opportunity, Scott is exposing many of his employees to a new kind of peer and colleague relationship, and the contributions a person with a disability can make.”

Matt Belanger and Paul Shew

Matt Belanger accepted the Corporate Support Award on behalf of Faraci Lange Attorneys. Faraci Lange was chosen for this award by the Board of Directors of The Advocacy Center for their support of our organization through five years of high-level sponsorships of our annual fundraising event. Additionally, Stephen G. Schwarz, Managing Partner of Faraci Lange, has served as a volunteer member of the Board of Directors of The Advocacy Center for five years and is currently the Vice President. Mr. Schwarz has provided strong leadership to strengthen the effectiveness of our governing body and has demonstrated a long-standing personal commitment to people who have disabilities. Steadfast support from Faraci Lange allows us to work toward our vision of Creating a World that Works for Everyone.

An Evening of Art and Jazz photos provided by J. Cruz Photography and Sarah Stein.
**The Advocacy Center**

**Celebrates New Staff**

**Cindy McCafferty**  
**Medicaid Service Coordinator**

Cindy attended SUNY Geneseo and graduated with a BA in Sociology. She has worked for Mary Cariola Children’s Center, The Arc of Monroe, Strong Hospital and Thompson Hospital. “I enjoy my role as a Service Coordinator because I am able to work closely with the individuals and their families to help them achieve their identified goals.” Cindy has lived in Rochester for 6 years and will be married in September. Welcome Cindy!

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**Annual Report Available**

The Advocacy Center’s Annual Report for 2010: Creating a World that Works for Everyone is now available. To receive a copy, contact Seneca Brashear at 585-546-1700 or brashear@advocacycenter.com.

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**Upcoming Events and Workshops**

**Understanding Difficult Behavior in Young Children ~ A Workshop for Child Care Providers**  
August 1, 2011  
6:30 PM to 8:30 PM  
The Advocacy Center, 590 South Avenue, Rochester, NY 14620

Crying, kicking, biting... What’s going on?? What are children telling us when they behave in this way? These challenging behaviors are a form of communication in young children. When we approach children with this mindset, we can better understand and help them to change their behaviors. In this workshop, we will discuss the typical goals of behavior and how we, as adults, can choose responses which support children and encourage acceptable behavior.

Pre-registration is required; participant fee of $30.  
To register by phone, 585-546-1700 ext. 399, Fax: 585-546-7069  
www.advocacycenter.com  
Attention: Seneca Brashear

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**Lay Advocacy**

Five Session Series ~  
Wellsville, NY (in progress)  
Saturdays, 9:45 AM - 2:45 PM,  
July 9, 2011 - August 13, 2011

The Advocacy Center announces a free, five session training for parents of children with disabilities. Priority will be given to parents whose children have developmental disabilities. If there are openings available we will open it up to parents whose children have other disabilities. Participants are selected through an application process. No class on July 16, 2011.  
Location: Jones Memorial Hospital, Walchli Education Room, 191 North Main Street, Wellsville, NY 14895.

To request an application, or for more information, contact Linda Chadderdon at 1-800-650-4967 ext. 225 or email chadderdon@advocacycenter.com.

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**Pro Social Behaviors and Sexuality**

August 24, 2011, Lyons, NY  
10:00 AM-12:00 PM  
The Advocacy Center, 590 South Avenue, Rochester, NY 14620

Crying, kicking, biting... What’s going on?!! What are children telling us when they behave in this way? These challenging behaviors are a form of communication in young children. When we approach children with this mindset, we can better understand and help them to change their behaviors. In this workshop, we will discuss the typical goals of behavior and how we, as adults, can choose responses which support children and encourage acceptable behavior.

Pre-registration is required; participant fee of $30.  
To register by phone, 585-546-1700 ext. 399, Fax: 585-546-7069  
www.advocacycenter.com  
Attention: Seneca Brashear

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**Parent Leadership for Parents of Infants and Toddlers with Disabilities**

September 17, 2011 - 9:00 AM to 1:00 PM  
Note: Sessions available both in Carmel and Binghamton, NY.

You are a leader! Attend a parent leadership session for parents of infants and toddlers with disabilities. Sessions are intended for parents of children under 3 with disabilities and parents who are interested in community leadership activities such as supporting other parents or serving on a Local Early Intervention Coordinating Council. Early intervention professionals may also attend as space allows.  
To register, call 800-650-4967 ext 399 or email registration@advocacycenter.com. Pre-registration is required!
EVENT CALENDAR

For an up-to-date listing of events, go to The Advocacy Center’s website www.advocacycenter.com and click on ‘Events’, then ‘calendar’

2011 Rochester Press Radio Club Shining Star Award

Lou Brown presents
The Quest for an Ordinary Life: Preparing Individuals with Disabilities to Function Productively in the Real World of Work
Thursday, October 20, 2011
The Strong Museum of Play
Speaker: Lou Brown, PhD
Professor Emeritus at University of Wisconsin
Lou Brown’s inspiring and informative presentation features strategies and real life examples to support competitive employment for individuals with disabilities.
Please check website for registration and information updates: www.advocacycenter.com or phone (585) 546-1700.

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The Institute for Innovative Transition at the University of Rochester Presents…..
Summer Institute 2011: In Pursuit of Competitive Employment: Project SEARCH™ and Think College NY!

Keynote Speakers include:
Susie Rutkowski, Co-Director, Project SEARCH™, Cincinnati Children’s Hospital speaking on Project SEARCH™: A Partnership with Business and Education to Prepare Youth with Disabilities for Employment
and Meg Grigal, PhD., from Think College, Institute for Community Inclusion, UMass Boston, Co-Principal Investigator on the Office of Postsecondary Education funded, National Coordinating Center speaking on Think College: The Nexus of Employment, Learning and Life
Thursday, July 21, 2011 from 8:45-4:30 (Registration begins at 7:45AM)
RIT Inn and Conference Center
5257 W. Henrietta Road
Henrietta, NY 14467
This institute is for students, family members and professionals. Deadline for registration is July 11, 2011.
A limited number of scholarships for students/young adults and family members available, based upon financial need.
Questions? Contact Anitra Medlock, Training and Outreach Coordinator, Institute for Innovative Transition
Anitra_Medlock@urmc.rochester.edu
585-276-5915

Success from the Start: Strategies for the Journey to Adulthood
A Day of Inspiration and Learning for Individuals with Disabilities, Family Members and Professionals
Saturday, September 24, 2011 • St. John Fisher College
Keynote Speaker: Loujeania Bost, PhD
Director, National Dropout Prevention Center for Students with Disabilities (NDPC-SD) at Clemson University
Success stories and best practices, breakout sessions on educational strategies, family issues, community inclusion and employment
Topics apply to all ages from infancy to adulthood.
Presented in conjunction with the Ralph C. Wilson, Jr. School of Education at St. John Fisher College
Please check website for registration and information updates: www.advocacycenter.com or phone (585) 546-1700.

New Conference!

Regional Event…

Jacob Noyes, recipient of the 2011 Shining Star Rochester Press-Radio Award, with Debbie Salmon from School of the Holy Childhood, presenting the award and Rochester Redwings mascot, Spike. Jake was honored for having an inspiring attitude in the face of adversity, as well as his noted progress within his educational program. Congratulations Jake!

The Rochester Press-Radio Club consists of sportswriters, television sportscasters, radio personalities, and community members who share an interest in sports and fundraising for local charities associated with children. For further information about the club, please visit www.pressradio.org.

Regional Event…

The Institute for Innovative Transition at the University of Rochester Presents…..
Summer Institute 2011: In Pursuit of Competitive Employment: Project SEARCH™ and Think College NY!

Keynote Speakers include:
Susie Rutkowski, Co-Director, Project SEARCH™, Cincinnati Children’s Hospital speaking on Project SEARCH™: A Partnership with Business and Education to Prepare Youth with Disabilities for Employment
and Meg Grigal, PhD., from Think College, Institute for Community Inclusion, UMass Boston, Co-Principal Investigator on the Office of Postsecondary Education funded, National Coordinating Center speaking on Think College: The Nexus of Employment, Learning and Life
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Please check website for registration and information updates: www.advocacycenter.com or phone (585) 546-1700.

New Conference!
After High School: Post-Secondary Educational Options

Western NYS/ Finger Lakes College-Based Programs

College-based programs are diverse. They may include partnerships between a school district, university, adult agency, or business.

***For a full description of individual programs, please see www.thinkcollege.net website or visit each university or program website. Each program offers its own unique combination of curriculum, support, entrance requirements, academic opportunities, social opportunities, residential options, credentials upon completion, etc.

Alfred University, Alfred, NY
ACCESS at Alfred University, contact Ann Monroe Baillargeon, Chairperson Education Division, e-mail: monroe@alfred.edu
Affiliated Public School: Greater Southern Tier BOCES, Bush Campus. Contact Cynthia Drake, Director of Special Education and Itinerant Services, E-mail: cdrake@gstboces.org

Geneseo State University of New York at Geneseo, Geneseo, NY
LIVES Program, 585.245.5351 Website: lives.geneseo.edu Contact: Elizabeth Hall, LIVES Program Coordinator, E-mail: halle@geneseo.edu

Hobart and William Smith Colleges, Geneva, NY
HWS College Experience, 315.781.4035, Contact Mary Kelly, Director Of Special Education, E-mail: Kelly@HWS.edu

Keuka College, Keuka Park, NY
Keuka DRIVE program, 315.279.5342 Website: Keuka.edu/experiential Contact Dr. Ann Marie Guthrie, Dean of Experiential Education E-mail: aguthrie@keuka.edu
Affiliated Public School, Penn Yan Central School District, Contact Dick Shaver, Director of Student Support Services E-mail: dshaver@pennyan.k12.NY.us

Nazareth College, Rochester, NY
LifePrep@Naz, Website: http://www.naz.edu/center-for-civic-engagement/lifeprep-naz?searchterm=LifePrep or www.arcmonroe.edu
Affiliated Public School: Victor Central School District Contact: Jaime Vella, Community Outreach Coordinator, The Arc of Monroe County, E-mail: jvella@arcmonroe.org, 585-730-6037

Niagara County Community College, Lockport, NY
People Inc. Young Adult Life Transitions Program (YALT) 716.439.8044 Contact Heather Coleman, E-mail: hcoleman@people-inc.org

Roberts Wesleyan College, Rochester, NY
Bridge to Learning, Earning, Living, Contact David Basinger, PhD, Bridge Program Director (585) 594.6570 E-mail: BasingerD@nes.edu
Affiliated Public School: Monroe #2 BOCES, Contact Donna Graham, 585-617-2907, E-mail: dgraham@monroe2boces.org

St. John Fisher College, Rochester, NY
West Irondequoit/Webster Post Secondary Program 585.233.8542, Contact Theresa Zona, Consultant E-mail: tzonal1@rochester.rr.com

University of Rochester, Rochester, NY
Post Grad Program, Contact Kristen Love, Coordinator for TPSID UR Project E-mail: kristen_love@urmc.rochester.edu
Affiliated Public School: Monroe #1 BOCES, Contact Joann Genthner, Administrator for Post Grad classroom E-mail: Joann_Genthner@boces.monroe.edu
Innovative Model: Project Search

Project SEARCH™ high school transition program is a school-year program for 18-21 year olds with developmental disabilities that provides training and education leading to competitive employment. It serves as an alternative for students in their last year of high school. The cornerstone of Project SEARCH™ is total immersion in a large business. For further information, please visit: www.nytransition.org/Project-SEARCH. Local collaboration includes Wegmans Food Markets, University of Rochester Medical Center, and the City of Rochester. For further information, contact Susan Hetherington, Project SEARCH™ Director. Susan_Hetherington@urmc.rochester.edu 585-275-6608 or Julie Christensen, Project SEARCH™ Coordinator Julie_Christensen@urmc.rochester.edu or 585-273-3713.

Day Service Options - Help with Terms

Post-Secondary Day Service Options for Individuals with Developmental Disabilities

From OPWDD – NYS Office for Persons With Developmental Disabilities  
www.opwdd.org

■ **Day Hab**: Medicaid-Waiver funded service for individuals with highest need level; provides services and supports to promote skill development; may include clinical supports such as nursing, OT, PT. Services include volunteer experiences to assist individuals to participate fully in their communities.

■ **Pre-Voc**: Medicaid-Waiver funded service that provides supports and training in preparation for employment, working on skills such as following directions, developing work attitude and habits, adjusting to workplace demands, communication, and understanding job requirements. The service is often provided in a Sheltered Workshop setting, but can be provided in the community in an individualized way.

■ **Blended Services**: Blend of Day Hab and Pre-Voc components to individualize a service to the needs of the individual.

■ **Sheltered Workshops**: Funded through a blend of state, county, and agency funding. Provides paid employment in a non-integrated setting, often through piecework that is contracted from community businesses. Wages are often below minimum wage and employees are paid in accordance with the Fair Labor Standards Act. Transportation may or may not be included.

■ **Supported Employment: (SEMP)**: Service that supports individuals in competitive employment in their communities. The employer pays the wages, and the individual receives training from a job coach to learn job tasks, practice appropriate work behaviors, communicate effectively with coworkers and supervisors, and learn to get to and from work independently. Service begins with a referral to VESID from the school during the last year of school; VESID provides funding for the intensive phase of job development and stabilization on the job, and then Medicaid-Waiver funding continues the service for the follow-along phase. (Please note: VESID is now called ACCES-VR. ACCES-VR provides vocational counseling and rehabilitation services that result in successful employment outcomes for individuals with disabilities and their employers, www.acces.nysed.gov/vr.)

■ **Employment Training Program/Internships**: Like supported employment, but NYS pays the wages for up to 18 months while the individual learns the job, and the employer agrees to hire the individual once they are able to effectively perform the job. Job coaching supports may initially be provided at an intensive level, and phased down as the individual’s skills improve; supports may continue as needed after the individual is hired. This is an employment option for individuals who may need a longer time to fade job coaching supports, and provides an incentive to employers who may have reservations about hiring an individual with disabilities.

■ **Enhanced Supported Employment**: A pilot program initiated in 2009 to promote employment for individuals who require supports not usually provided as part of traditional SEMP service (such as personal care, behavior management, increased level of supervision, health/medication management). The service provider receives a higher level of funding than available through SEMP in order to be able to provide the enhanced services.

■ **Individualized options**: Service providers are being encouraged to be more innovative in how they deliver services, with a focus on developing creative, lower-cost options that are customized to meet individuals’ needs. Planning for an individualized services requires the person to be able to define what it is they want; the service coordinator, family, individual, service provider, and DDSO can work together to design a unique service.

For more information about any of the above or assistance in planning contact: Pat Barry (585) 461-8826 pat.barry@opwdd.ny.gov
Rochester Community-Based / 
Agency-Based Programs

This represents only a partial list of many local community-based programs and services.

**Arc of Monroe County**
DayHab: Contact Community Outreach Coordinator at 585-271-0660, ext 2037.
Transition Services: Contact Kathy Moylan, Senior Administrator for Transition Services, at 585-698-1331
Job Path services, contact Job Path Director at 585-256-7330, ext. 2510.
(Also See Nazareth College LifePrep@Naz)


**Catholic Charities Community Services**, Rochester, NY
Contact Kathleen Termine, Developmental Disabilities Services Director 585-339-9800 Ext 227. Email cccs@dor.org website: http://www.cccsrochester.org/

**Continuing Developmental Services, Inc. (CDS)** Webster, NY 585.341.4600 website: www.cdsunisel.org. Transition services and Day Services, Contact Kim Stockmann, 585-341-4817. Self-Determination: Contact Amy Popeck, Director of Community Services, (585) 347-1035.

**Easter Seals**, Rochester, NY (585) 292-5831 Email lvanderhoof@eastersealsny.org website: http://www.easterseals.com Services include Medical Rehabilitation and Workforce Development.

**Heritage Christian Services**, Rochester, NY, Phone (585) 340-2000 or visit www.heritagechristianservices.org to view a wide variety of activities coordinated by program: Day Hab, Respite, Service Coordination, and Health Services.

**Hillside Family of Agencies**, Rochester, NY, (585) 256-7500 Email info@hillside.com website: http://www.hillside.com/ Offers wide variety of services including Service Coordination, Plan of Care Support Services, and In-Home Residential Habilitation

**Ibero-American Action League**, Rochester, NY (585) 256-8900 Email information@iaal.org website: http://www.iaal.org/ Services include Service Coordination, Individual Support Services, Day Habilitation, and Supported Employment

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A Journey into Adulthood
By Kathy Terrillion

Stephen Terrillion, age 20, volunteered many hours over the last two months organizing and taking inventory of all the books, dvds, cds, and videos available in The Advocacy Center lending library.

It has been a lifelong journey for Stephen to transition into an adult who has the ultimate say in how he wants to live his life, do work that fits his skills and motivates him to earn money, have fun in his own way, and to be with people he prefers at activities he enjoys. All this, and yet have manners, understand consequences of his actions, and to take responsibility for himself to push through challenging behaviors.

It has been a challenge finding the right environments that minimize stresses on Stephen so that he could develop his social skills as a child and as an adult. Through our family efforts, he has found a natural fit into alternative communities that embrace all ages and abilities. Stephen works and socializes within his organic farming community and other cooperatives that support similar untraditional goals and lifestyle. Stephen continues to volunteer his time to support Camp Chin-Gu, a cooperative Korean culture camp that he enjoyed as a young camper for many years.

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A Journey into Adulthood continued from page 9

At 20, Stephen’s future plans include 1) remaining in his home while transitioning into an adult family member, and 2) developing a self-employed business he can perform at home working hours that suit his needs.

At age 16 Stephen began Person Centered Planning and Self-Determination as his transition path. PCP has allowed for exploration of alternative ways to find volunteer opportunities, such as organizing the lending library at The Advocacy Center.

Stephen’s transition to his adult self has been a history of trying many different therapies and programs, and our willingness to stop what was not working and persevering with what was working for him. The top successes for Stephen have included 1) immersing into the Greenspan/Wieder floor time play that emphasizes family interactions to mobilize development and growth, 2) incorporating supports for his multiple sensory processing issues, 3) special diet to reduce the more severe symptoms of autism, 4) plenty of heavy work in fresh air to improve his very poor muscle tone, 5) improving air quality in the home and switching to non-toxic cleaning supplies, 6) listening therapies (Tomatis and Enlisten), 7) joining communities as a family that support his lifestyle and interests, 8) giving him more control over his life to follow his own developmental time table, and 9) taking advantage of every support and workshop available from The Advocacy Center, which continues to be a powerful influence in our lives as a family and for Stephen as an individual.

In order to deliver the intensity and variety of opportunities Stephen needed for his overall development, we began to home school Stephen at age 7. Home schooling has allowed Stephen to transition into a world he can live with and even enjoy. Stephen needed to spend much of his time within the nurturing environment of home and to devote a lot of time experiencing the community naturally on his own terms while learning to adjust to the world. With home schooling we were able to give him the consistent guidance and discipline that made sense to him.

The umbrella over all these successes for Stephen was following guidelines for his Hyperlexia (very early decoding of written language coupled with disordered language). We began by writing to Stephen when he was only 4 1/2 years old, the very day we learned of his Hyperlexia. Now he has updated technology that is affordable and accessible – iPad with Proloquo2go, Oxford dictionary app (concrete definitions) and other inexpensive apps to help support and grow his language. We utilize other programs that convert spoken language into written language, including C-Print (very reasonably priced to learn and own right from RIT/NTID) and Dragon Naturally Speaking which is convenient for home use.

A means to communicate in an efficient and effective manner has been essential in helping Stephen control his behaviors and transition himself into a life he can call his own. Of note, Stephen did not have access to communication technologies that have been most effective in stressful situations until he was nearly 19, proving to us that when the right supports are provided, regardless of age, anything is possible.

…when the right supports are provided, regardless of age, anything is possible.

News You Can Use

Application for Young Adult/Leadership Sponsorship

The New York State Independent Living Council, Inc. (NYSILC) is conducting outreach to young adults with disabilities (age 18-28) with demonstrated leadership potential. Sponsorships of up to $250 each will be awarded to youth based on cost and need. For an application, please visit http://www.nysilc.org. Complete applications are needed to make decisions regarding the sponsorships. Electronic format is preferable and allows equal access for NYSILC members to easily review the information. If you have any questions related to the application, contact the NYSILC office at (518) 427-1060 (Voice/TTY), 1 (877) 397-4126 (Toll Free NYS Only), (518) 427-1139 Fax, or jfaringer@nysilc.org. Return completed applications to: jfaringer@nysilc.org.

Free Whitewater Kayaking Clinic Open to City Residents

Kayak Adventures and the City of Rochester Bureau of Recreation are hosting three-day whitewater kayaking clinics in July and August. The clinics will be free to city residents. Eight sessions are available. For more information and to register, contact Kayak Adventures at 704-2372 or email kayakadv@rochester.rr.com or visit www.kayak-adventures.org.

Fetal Alcohol Spectrum Disorders (FASD)

For information on Fetal Alcohol Spectrum Disorders, please contact: National Council on Alcoholism and Drug Dependence- Rochester Area Jennifer Faringer, Director of NCADD-RA 1931 Buffalo Rd, Rochester, NY 14624 Phone: (585) 719-3480; Fax: (585) 423-1908 Email: jfaringer@depaul.org Website: www.ncadd-ra.org.
Class of 2011 is in full swing!

By Jackie Yingling

Approximately 60 family members and self-advocates are forging new territory by utilizing an interactive web-based learning platform. The group has been meeting “on-line” for content delivery since March. They are busy sharing information, support, and thoughts on content with each other on a regular basis through forums, chats, and webinars.

A small group of participants met in Ithaca at Cornell University for sessions on Creating Vision and Building Community. At the same time approximately 30 participants logged in from their homes during various times over the weekend. During the presentations, the group at Cornell was able to interact with Partners participants at home. Despite a couple of technical glitches, the weekend was deemed a huge success.

The class members are creating strong bonds with one another, and are currently working together on the fifth of eight curriculum modules. Applications for the 2012 Class of NYS Partners will be available on www.nyspip.org in August.

At the same time, the Partners Graduate network continues to grow. Opportunities for trainings and webinars are frequently offered to the graduates. Visit www.nyspip.org for more information.

From the Editor

In April, I attended a LifePrep information session and tour at Nazareth College, the most recent college in Western NY to offer a post-secondary college-based experience to students with intellectual disabilities. LifePrep is modeled after programs at Penn State University and Keuka College. Nazareth College offers Life Prep in partnership with Victor Central School District and The Arc of Monroe.

While each post secondary college-based program for students with disabilities is unique, many of them collaborate with both a local school district which supervises the Individualized Education Program (IEP) and an agency providing guidance in adult services. The curriculum may include any combination of life skills coursework, academic coursework, work experience and training, peer mentoring, access to campus activities and facilities, and access to agency services.

As I listened to the presenters describe their new program with pride, observed the interest and zeal of potential students, and joined in the campus tour led by a Nazareth student, I was filled with enthusiasm. One thought never left my mind:

Thank you to the parents who came before me to make this dream a reality.

The post-secondary opportunities available today for people with disabilities, whether they are college-based or community-based, were first envisioned by parents or other family members who then shared their vision with professionals. Parents and professionals worked together over time to create the many options we now see in place or in progress.

When my son Nick was born and diagnosed with Down syndrome, college was one of those dreams for him I found very hard to let go. That was 19 years ago. I never imagined I would ever hear Nick say, “I am going to college.”

Maria Schaertel
Upcoming titles from Woodbine House:

**Expected December 2011**

**The Girls’ Guide to Growing Up – Choices & Changes in the Tween Years**
By Terri Couwenhoven, M.S.
The Girls’ Guide to Growing Up is written by an experienced sex educator who specializes in working with people with intellectual disabilities and who is also the author of Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality. Parents, physicians, schools, and support groups will want to share this encouraging book with girls to help answer their questions about puberty and reassure them it’s all part of growing up.

**Expected September 2011**

By Mary Jane Weiss, Ph.D., BCBA-D & Valbona Demiri, Ph.D., BCBA-D
Jumpstarting Communication Skills in Children with Autism describes how an ABA approach can help children age 2-10 who have significant communication problems—difficulty making requests, perseverative speech, a lack of fluency in conversational exchanges, trouble reading others’ signals, and more—learn to understand and use speech and language.

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