



EFR Joins March to Celebrate the 20th Anniversary of ADA

Nine EFR employees and an EFR board member were proud to be among the approximately 400 individuals who marched from the Arise building on James Street to the OnCenter on July 26th in celebration of the 20th anniversary of the Americans with Disability Act. This historic act guarantees equal access and opportunity for people with disabilities with respect to public accommodations, commercial facilities, employment, government services, telecommunications and transportation.

Local officials who spoke at the OnCenter event proclaimed July as Disabilities Awareness Month in Onondaga County. Among the officials in attendance were Mayor Stephanie Miner, County Executive Joanie Mahoney and United States

Congressman Dan Maffei.

Many agencies — including EFR — also staffed information tables at this ADA event.

For more information about the ADA, see ACROSS THE NATION, page 3.



Photo by Dave Wissink

ADA Celebration Representative, Deb Gibson-Jaworski, and Board Member, John Fix, lead EFR employees down James Street.

Figuring Out What to Do

A Message from our Executive Director

What to Do?

“If you can keep your head when all about you are losing theirs...”

I have never been all that “into” poetry, but, in recent months, I have often found myself silently quoting the first line of Rudyard Kipling’s famous poem “If” when dealing with various issues regarding our services. It is very evident that individuals and families receiving our

services, our staff and other key people in the service system have grown weary of hearing about the “challenges” ahead and the “unprecedented” financial problems. All of us have clearly been frustrated by what is happening to our services system, with huge cuts to service coordination and other reductions now adopted in the state budget. Unexpected changes seem to be a constant, such as Commissioner Diana Jones Ritter’s resigning after 3 years on the job. And honestly, there is very little that suggests a “light at the end of the tunnel.”

And that is where Rudyard Kipling comes into my mind. I believe that

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it is critical that we not allow despair to overshadow hope, and this is even more important when hope is even harder to find.

Believing something and actually doing something about it can be very different processes, however, especially when problems seem to be growing and becoming more intractable. So, we at Exceptional Family Resources are going to do more than just tell our staff to “put on a happy face.” We are planning sessions with our staff in the coming weeks to strategize about how

we can make sure the individuals and families receiving our services are offered positive options. We will neither assume that things will be all right nor conclude that nothing can be done, but will instead focus on ensuring that our staff know what is available and develop their skills in creatively putting things together for people.

Despite all the changes, there are still a lot of good things happening, with my personal favorite being a renewed emphasis on

employment for people with developmental disabilities. And, finally, there are also some changes—tentatively planned for November—coming to At Home Res Hab which will allow for a greater community focus. Perhaps such “good things” on the positive will not get us all to Kipling’s level of “Yours is the Earth and everything that’s in it,” but, they sure beat answering “What to do?” with a big “Nothing.”

Dave Wissink

Advocacy Workshop Schedule Fall 2010

• INDIVIDUALIZED SUPPORTED EMPLOYMENT

Pam Aspinall, Employment Services Supervisor
Exceptional Family Resources

Tuesday, October 5, 2010

• BRAIN INJURY BASICS

Brian Rieger, Ph.D., Director of Rehabilitation Psychology
SUNY Upstate Medical University

Tuesday, November 2, 2010

• SPECIAL NEEDS TRUSTS

Rick Cote, Jr., Chartered Financial Consultant
New England Financial

Tuesday, December 7, 2010

All workshops are held in the 2nd Floor Board Room of Exceptional Family Resources from 6:00 to 8:00 p.m.

The registration fee is \$5.00 per workshop, payable at the door. Dinner is included with all workshops.

Reservations must be made at least one week in advance of each workshop. For more information or to register, call Sue Corcoran at 478-1462, ext. 327.

Reaching for the Stars 2010: A Good Day for All

“Social Skills and Developmental Disabilities,” EFR’s 2010 Reaching for the Stars Conference, took place at Justin’s Grill on May 21st. Speaking to a sold-out crowd, Dr. Susan Scharoun, Chair of the Psychology Department at LeMoyne College, gave an informative, story-filled and often humorous presentation which highlighted the importance of social skills among all people and provided methodology for enhancing the social skills of those who have developmental disabilities. Conference evaluations were overwhelmingly positive with respect to the topic, the speaker and her presentation, and the venue.

If you have thoughts or ideas about topics or speakers for next year’s conference, please contact Anne Winschel at (315) 478-1462, ext. 323, or awinschel@contactefr.org.



Dr. Susan Scharoun, May 21, 2010

Photo by Helen Singh

Newsflash

AROUND THE WORLD

During the major reconstruction that follows a large number of disasters, planners often miss opportunities to avoid recreating the exclusion of people with disabilities by adapting the design of the buildings and environments. It is far more cost-effective to modify the plans for a new building at the outset than to adapt an existing building to make it accessible. Depending on the type of building, providing full access facilities from the outset costs only an average additional 1.12%.

For these reasons, the **Global Partnership for Disability and Development (GPDD)** started a **Working Group on Haiti Reconstruction**. The Aim of the Working Group is to ensure that reconstruction efforts after the Haiti earthquake involve people with disabilities during all stages and that all rebuilt and newly built infrastructure entities are fully accessible and usable by people with disabilities. The participants of the Working Group are currently working on a “Toolkit on Inclusive Reconstruction.”

The GPDD also co-sponsored a panel discussion on “Haiti: Reconstruction for All” during the International Donors’ Conference for Haiti in the Spring of 2010. The panel presented the current needs of people with disabilities in Haiti, the long-term benefits of building an inclusive society and the development of sustainable service delivery systems for assistive technologies. (<http://www.un.org/disabilities/default.asp?id=1533>)

ACROSS THE NATION

Senator Tom Harkin (D-Iowa), Chairman of the Senate Health, Education, Labor and Pensions (HELP) Committee, introduced a resolution on July 22, 2010 recognizing the **20th anniversary of the Americans with Disabilities Act (ADA)**. Harkins was the author of the ADA and its chief sponsor in the Senate. **Senator Orin Hatch (R-Utah)** is the Resolution’s chief co-sponsor. This current resolution salutes those people whose efforts contributed to the enactment of the ADA, and encourages as many people as possible to celebrate the freedom and opportunity provided by the ADA and pledges to continue to work on a bipartisan basis to address the remaining barriers to

equal opportunity for individuals with disabilities. The introduction to the Resolution states that “the ADA has broken down barriers, created opportunities and transformed lives. Today, we recognize that people with disabilities--like all people—have unique abilities, talents and aptitudes. The ADA is America at its best.” (<http://www.iowapolitics.com/printerfriendly.html>)

The **House of Representatives** is currently holding hearings on H.R. 3101, “**The Twenty-first Century Communications and Video Accessibility Act of 2009.**” This bill was introduced by representative **Edward Markey (D-Massachusetts)** who has testified that “Americans with disabilities

should have access to the communications technologies of (the) 21st century, and delays are unacceptable....There is no better way to honor the 20th anniversary of the ADA than to move this bill forward.” Among the requirements of this bill in its current form is the requirement that every provider of Internet access service and every manufacturer of Internet access equipment, unless it would be an undue burden, make user interfaces accessible to individuals with disabilities. This bill resides in the early stages of the legislative process; it recently moved from an HR subcommittee to the HR full committee. (<http://hlaadvocacy.blogspot.com/2010/06/hlaa-to-testify-before-us-house-of.html>)

THROUGHOUT THE STATE

A New Name!

On June 18, 2010, prior to her resignation, then Commissioner, Diana Jones Ritter sent the following letter:

Dear Friends and Colleagues:
WOW! Finally, some good news to tell you: Change is coming!

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I am extremely pleased to let you know that both the State Senate and the Assembly have now passed our name change bills – as soon as the Governor signs them into law, OMRDD officially becomes the **New York State Office For People With Developmental Disabilities (OPWDD)**!

This vital legislation not only removes the words “Mental Retardation” from the name of the State agency, but also from State statute

and regulations, excluding clinical references.

Since the beginning of my administration, I have wanted to make this change in support of the individuals with developmental disabilities and their families. This is the culmination of all the work individuals, families and providers have done to advocate for dignity and respect for all people with developmental disabilities.

I am incredibly delighted about this vital milestone that greatly supports our mission of helping people with developmental disabilities live richer lives.

We will be making a more formal announcement in the very near future! Stay tuned!

Sincerely,

Diana Jones Ritter

IN OUR COMMUNITY

An excerpt from an August 2010 Post-Standard editorial highlights good-things-to-come:

“There’s a long, long trail a-winding ...”

“Well, some day there may be a trail winding 10 miles along Onondaga Creek through the city of Syracuse.

Imagine the Onondaga Creekwalk as a serene, scenic waterside path, wide enough to accommodate pedestrians, skateboarders, in-line skaters, bicyclists and **people with disabilities**.

That vision took shape back in the 1980s. Yet today, it is a short, short trail a-winding: barely two-thirds of a mile of the creekwalk is finished. Still, it’s enough to give a tantalizing glimpse of what could become a unique recreational asset, reviving interest in the city and its natural environment.

There’s a long way to go. The lake loop trail is not yet a reality. The downtown section of the creekwalk, which began construction in November, is expected to be done by the end of the year. The 2.2-mile Armory Square-Onondaga Lake span could be in place by next summer.

But if you want to get a feel for what’s in store, take a walk or ride along the completed stretch of creekwalk in Franklin Square. You’ll cross a couple of bridges that offer great views of the creek in its natural state.... With birds singing and water flowing, you may even forget for a moment you’re in the heart of a mid-sized city.

Raising Onondaga Creek’s profile as it winds through Syracuse presents logistical challenges. But...with the creekwalk...under way, there’s new promise in the air.”

http://blog.syracuse.com/opinion/2010/08/onondaga_creekwalk_in_view_nex.html

Change Among Us

EFR bids a fond FAREWELL to longtime members of our Administrative Department, **Kathy Pierson** and **Wanda Baum** as well as MSC, **Joan Travis**, all of whom retired in December. We thank them for their years of hard work and dedication.

EFR also bids a warm WELCOME to new office employees **Kimberly Chappell**, Director of Finance, and **Irene Fiesinger**, Respite Coordinator.

GET EFR?

Our new address is:
1820 Lemoyne Avenue
Syracuse, NY 13208

Our website remains:
www.contactefr.org



A Mother — and her Daughter — Figure Out the Bike

By Deborah Cavanagh

As a parent of a child with special needs, you are inundated with professionals, Internet information and connections, and other parents offering advice. All of this can be overwhelming, but often it makes sense to rely on others' strategies.

Our family looked to the experts for help in an area where we had hit a wall...two wheeler bike riding. My daughter, Amanda, had learned to ride with training wheels. At thirteen, she longed for the independence of a two wheeler but was too afraid to even attempt to learn. I researched and found the Lose the Training Wheels Bike Camp. This program, created for children with disabilities, is built on the principle that training wheels don't actually teach the children to balance properly. A group of trainers tour the country with local volunteer help to conduct the one week program. I had heard positive reviews, so we decided to give it a try.

I wish I could say the adventure was a rounding success. Each day, I watched from the stands as trainers and volunteers taught Amanda how to use the trainer bikes. I sat through parent information meetings to learn how to support her once we got home. I watched as children in her session, on day three, were able to tool around the arena on a two wheeler for the first time. On day four, almost all the children, demonstrating various stages of independence, graduated to the outdoor track. I say "almost" since Amanda had gotten to the point where she was refusing even

to get on her bike. She was fine going around on the trainer, but when the powers that be decided she was ready for the move to "the two wheeler," she balked. I slunk deeper into my seat as I watched them battle with her. Every single volunteer gave it a go. Unfortunately, they played into all her task avoidance strategies as she messed with her helmet, said the seat felt weird, wanted the boy trainer to help her and asked for a drink. I scooped down further in my seat as I saw them glance in my direction. Then finally the frustrated head trainer made her way over to me. "Do you want to give it a try? She just won't get on the bike."...now I am thinking, this is why I paid you the big bucks....if I could get her to ride a bike, I wouldn't even be here. "OK, I will give it a go," I said, as I headed down the stairs and out to the rink. Amanda saw me coming and knew the fun was over. The last day it was just Amanda and I, and, finally, with much yelling on her part, and Jedi mind tricks on mine, she went around the rink and graduated to one loop around the outdoor track. She received her trophy as if she had just won the Tour De France. The head trainer came over to me and said, "All success is individual." Really? I wondered....what success are we talking about here?

That could have been the end of our bike riding adventure, but as you have guessed, it was not. Even though Amanda didn't really "graduate" from bike camp as a rider, I absorbed new strategies that worked on kids who never thought they would ride. Given this ammunition and my stubbornness born of

knowing I spent \$100+ on the camp, we took to the street every day. I have learned that the professionals present you with the tools. It is up to us as parents to take these tools and work with our children in a way we feel will help them. Our children may not fit the program, even if the program is designed for children with special needs. I cannot just assume that any program will automatically work. I know my child best, and I need to modify, follow up and follow through. It will take time and effort on my part, and maybe even more adapting based on my understanding of who Amanda truly is.

I am proud to say that Amanda is now riding unassisted around good portions on our street loop. She can stop on her own, and we are working on starting. Yes, this is where most kids were when the camp ended. Am I sad that it has taken much longer for her to reach this point? Absolutely not! She has made steady, proud, Amanda progress, and that alone is success!

Deborah Cavanagh is the parent of two children. You may visit her blog at: momofmanyneeds.com.



Dad, Brian, accompanies Amanda on a ride.

Photo by Deborah Cavanagh

Topics for Teens and Transitioning Students

Creating a Path to Employment:

Tips for Parents of Children with Disabilities

Start Early

Start by conveying your expectations that he/she can and will work when he/she grows up. Provide opportunities for your child to gain experience through volunteer work in your community. Websites may be helpful when exploring career options. See Career Voyages at www.careervoyages.gov as an example.

Promote Education

When parents expect their children with disabilities to continue their education beyond high school, the children tend to receive better grades than their peers whose parents do not have these expectations. In addition to the basic skills, your

child learns how and when to tell others about any accommodations he or she may need.

Encourage Work-Based Learning Experiences

Schools and community-based organizations may offer internships, job shadowing, and mentoring opportunities that focus on employment. Both postsecondary education and vocational education classes can expose young people with disabilities to careers and prepare them for work.

Create Leadership Opportunities

Encourage your child to become a mentor to younger youth. Participation in sports, student government, chorus, or volunteer groups can also build leadership skills. There are also a few leadership organizations specifically focused on youth with disabilities including the National Youth Leadership Network

(www.nyln.org) and the National Consortium on Leadership & Disability for Youth (www.nclld-youth.info).

Set Goals

Teach your child how to set goals and work towards achieving them.

Develop Social Skills

Through the day-to-day activities that accompany making and maintaining friendships, you will be assisting your child in developing the ability to interact and get along with others, another essential skill employers look for and value in an employee.

Adapted from a publication on the U.S. Department of Labor website www.dol.gov, [Creating a Path to Employment](#).

EFR's Pilot Employment Program Hoping to Expand

EFR is currently running its "CAREERS" pilot program. CAREERS is an acronym for Capable, Able and Ready-Employment for Everyone through Real Solutions. This program is designed to assist adults with developmental disabilities who require high levels of support and cannot be served through traditional services such as VESID.

CAREERS helps these individuals transition into the world of work by assisting them in obtaining and maintaining meaningful employment. The level of support offered to the employee, the employer and co-workers through CAREERS is intense, individualized and person-centered.

We currently have all eight pilot slots filled; pilot participants are employed, and additional individuals have been placed on a waiting list. Because our pilot program has

been such a success, we are currently searching for additional funding through OPWDD's Consolidated Supports and Services (CSS) program which would allow us to support additional participants who would like to work. If additional funding is secured, the expanded program's intent is to mirror the services and approach that are being utilized in our CAREERS pilot program. Like CAREERS, the expanded program would use a positive, team approach whenever possible so that the CSS-funded services wrap around the

Pilot, Continued on page 7

individual and support him or her in reaching specific goals and objectives. Vocational person-centered plans would then be created and used to assess an individual's strengths and challenges, and to determine appropriate supports and employment environments.

As with the pilot, additional funding would give possible tax incentive eligibility to employers who provide first-time jobs to any new CAREERS participants. Making good job matches provides a win-win situation for everyone involved. Employers will

benefit by having an employee who is dedicated and proficient at assigned tasks and who offers a different perspective. Support staff is provided not just for the individual, but for the employer and co-workers as well.

Editor's Remarks

While the move to our new offices provided all of us with more space in a global sense, I found, to my surprise, that my own office in the new building was significantly smaller than the office I occupied at 1065 James. This fact necessitated my making some significant choices regarding what I would keep vs. what I would give to others, put in storage or simply throw away. I had to figure out a way to make myself "fit" in my new space.

Although I've never been very good at "letting go," I have to admit that the weeding out process was moving along fairly smoothly—that is, until I began the task of cleaning out my files. Truthfully, much within these files was easy to discard; the Internet has placed information at our fingertips, and that information is far more current than much of what I've been saving in a drawer since 1999. Additionally, my job has changed significantly since then, and there was much that I just wasn't using. As I proceeded to discard the contents of folder after folder, I convinced myself that, not only could I do this, but I was, quite frankly, rather good at it from an efficiency standpoint. Such confidence, however, met its demise as I pulled out what I call my

"Good Reads" folder. Stuffed to the gills, this folder has long been where I store written pieces that touch my heart, thoughtful perspectives that are worth far more than a quick glance, words on paper that tug at my sensibilities as I marvel at people's honesty, forthrightness, courage and strength.

Not surprisingly, little of what I've kept in my "Good Reads" folder is scientific or based on academic research. Rather, the folder's contents are best defined as letters, articles, cards and even quickly-jotted notes written by friends, colleagues, parents, kids and grown-ups with disabilities, and even people I've never even met. Some might say that this content is at best a potpourri of written expression, but I make the not-so-modest claim that such content is something with vastly greater potential. Reading—over and over again--what others have written can seemingly transform relationships: friends become family, colleagues become friends, parents become confidantes, people with disabilities become heroes and absolute strangers become soul mates. How then could I give up the opportunity to revisit these writers--the parent who has learned to cope and advocate for a child with disabilities, the young man

with a disability who has found his voice and knows that the world needs to hear what he has to say, the mother who gives poetic thanks for her support group, the physician who understands why our community needs a children's hospital, and, perhaps especially, the parent who writes with care and love about finding a residential placement for her son? Discarding any of their words seemed wrong, if not sacrilegious.

In the end, what I figured out was that it was all right to keep it all, that the entire "Good Reads" folder still had a home within my files. While Dave writes in this issue about EFR's figuring out how to provide individuals and families with quality services in the face of the state and county budget constraints, I know—as he certainly does—that we must not lose sight of the individuals, the families, the real people whose lives are intertwined with ours and whose faces are intertwined with the numbers on paper that challenge what we do. I am grateful for the person-centered focus that defines EFR. As for all of you—with and without disabilities—who make up the extended EFR community, I know that all of us are grateful for you as well. We hope the feeling is mutual.

Anne Winschel

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Parent to Parent of NYS

Connecting and Supporting Families of Individuals with Special Needs

EFR's Parent to Parent of New York State program matches parents — based on their request — with a trained support parent who has a child with a similar disability, chronic illness or health care concern to provide support, share information and help with parenting issues.

Parent to Parent offers parents of children with special needs the opportunity to help someone else by becoming a Support Parent. Every parent of a child with a disability has experiences to share that will assist another parent or family facing the challenge of a new diagnosis or parenting issues. **If you would like to learn more about being matched with another parent for support or information-sharing, or would like to offer your time to become a Support Parent, please join EFR's Parent to Parent Coordinator, Dru Nordmark, and other parents for coffee and questions on one or more of the following dates:**

September 24th, October 22nd & November 12th.

All meetings will be held at EFR in the conference room from 10 to 11 a.m.

Questions? Contact Dru Nordmark at 478-1468, ext 322 or dnordmark@contactefr.org

EFR's Mission Statement

Exceptional Family Resources partners with individuals with disabilities and their families, providing services, information, advocacy and other supports to enhance lives and foster community acceptance.