



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

## UPFRONT AND PERSONAL

### Siblings: Natural Leaders in Disability Advocacy

By Maria Schaertel

Along with individuals who have disabilities and their parents, the people who understand disabilities the best are brothers and sisters of those individuals. They grow up side by side, observing first-hand the unique challenges of both living with a disability and living with someone who has a disability.

Many siblings develop extraordinary sensitivity and knowledge of disabilities as well as a passion to help others understand. They are uniquely qualified to teach disability awareness. For example, siblings understand “people first” philosophy because they have lived it. Their brothers and sisters are *first brothers and sisters* and secondly, individuals who have disabilities. Another important aspect of disability awareness is communication differences. Many siblings have experienced



communication challenges and the accompanying behaviors sometimes associated with them.

With this in mind, eight teens and pre-teens including individuals with disabilities and siblings, gathered at The Advocacy Center in August to participate in a pilot program for future leaders of disability advocacy. With enthusiasm, the 11 to 18-year-olds participated in interactive, hands-on learning activities with the ultimate goal of understanding better the physical and emotional impact of disabilities. Even though the participants were mostly strangers to each other, they instantly shared a common bond: lifelong experience with disabilities.

Presenter Adam, who is non-verbal, used his communication device to introduce himself and answer questions from the group. Adam’s participation was very instructive for

the participants, many of whom had never seen a communication device or attempted communicating without conventional speech.

18-year old Natalie commented, “I didn’t realize a communication board actually works. I’ve only seen it on TV.”

12-year old Philip asked Adam if he could write his name - Adam was happy to demonstrate. Philip asked many questions and with newfound respect and understanding, resolved that if he

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## What’s Inside...

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Lou Brown presents  
**The Quest for an Ordinary Life**  
 Thursday, October 20



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**Siblings of Individuals with Disabilities**

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Top Row:  
 Kathleen Buick,  
 Andrea Schaertel,  
 Natalie Dixon,  
 Jacob Dixon,  
 Philip Greenauer  
 Bottom Row:  
 Samantha Brown,  
 Andrew Hecht,  
 Adam Szczesny (Presenter),  
 Jillian Arrington

# Advocacy Center News

## New Open Enrollment for The Advocacy Center Community Awards Nominations



The Advocacy Center Community Awards honor role models who demonstrate a commitment to individuals with disabilities. The awards seek to honor those who have made life better through their efforts on behalf of individuals with disabilities and those with disabilities whose lives serve as an example for others.

Award recipients are invited as guests to The Advocacy Center's annual fundraiser. Each recipient is introduced, recognized for his or her contributions and accomplishments, and is presented with an engraved award.

Beginning with the 2012 awards, nominations will be accepted year-round.

Nomination forms will be available in the *Spotlight* section of our website. Please visit [www.advocacycenter.com](http://www.advocacycenter.com) and click on *Spotlight*. For a paper copy of the nomination form, please contact: Rick Wright at (585) 546-1700 or e-mail: [wright@advocacycenter.com](mailto:wright@advocacycenter.com)

Laura Khederian, the 2011 Jeanne Krautwurst award winner, reflects upon her award experience:

*I was tremendously honored to receive the Jeanne Krautwurst award, honoring a parent of a child with a disability. I have worked hard to help Jimmy expand his opportunities. With the support of his dad, his sisters and other family members, his teachers and support staff, the folks at the zoo, and most importantly, JIMMY, together we have been able to convert those opportunities into successful experiences.*

## The Advocacy Center Collaborates with Cornell in Sibling Needs Assessment

The New York State Developmental Disabilities Planning Council (DDPC) is committed to identifying and assisting adult siblings of NYS residents with developmental disabilities. With support from the DDPC, the Employment and Disability Institute at Cornell University, in collaboration with The Advocacy Center, will:

- Develop and administer a survey on service delivery systems
- Conduct a needs assessment survey of adult siblings about their knowledge and care capacity for their sibling with developmental disabilities
- Engage in outreach identification efforts resulting in a database of adult siblings of NYS persons with developmental disabilities

Carrie Burkin, Parent Education Specialist at The Advocacy Center, will be a contributor to the project, slated to begin in Fall 2011.

*-With excerpts from Proposal Summary*

## The Advocacy Center Receives Award from U.S. Dept. of Education



August 11, 2011 by Paul Shew

The Advocacy Center has been awarded \$524,874 from the United States Department of Education, Office of Special Education Programs, for its Parent Training and Information Center, which serves all of New York State outside the five boroughs of New York City. The award is expected to continue annually for the next four years.

This grant allows The Advocacy Center, based in Rochester, to continue to operate the Parent Training and Information Center, first established in 1998. This center supports parents of children aged birth to 26, with all types of disabilities that affect their development and achievement in school. The Parent Training and Information Center provides workshops, information, and advocacy to parents through more than ten thousand contacts per year.

Congresswoman Louise Slaughter notified The Advocacy Center of the grant award this week. "I am delighted that The Advocacy Center has been recognized and will be able to continue their programming for parents of children with disabilities," said Slaughter, who wrote to the Department of Education in support of the Center's proposal. "They have a proven track record of helping tens of thousands of parents of children with a wide range of disabilities. The Advocacy Center's most recent annual report showed that one-hundred percent of the people surveyed reported that Advocacy Center workshops' provided them with the information they needed to make decisions about their child's education. Ninety-nine percent of people surveyed reported that because of the information they received at the workshop, they are more knowledgeable about how to work with schools. It is a terrific program and one I'm so pleased to see offered across New York State."

# Advocacy Center Upcoming Events & Workshops



*Lou Brown is coming to town!*

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.*

For further information, please see:  
[http://www.advocacycenter.com/pdf/10202011\\_Lou\\_Brown.pdf](http://www.advocacycenter.com/pdf/10202011_Lou_Brown.pdf)

REGISTRATION INFORMATION:

Registration is required. Deadline - 10/13/2011  
Registration Rate: \$79, Special Rate: \*\*\$50\*\* Only for Individuals with Disabilities, Family Members and Students  
Limited scholarship support may be available for individuals with disabilities and family members, provided by New York State Developmental Disabilities Planning Council. Scholarships will be awarded on a first come, first served basis.  
Day of Conference Walk-in Rate: \$85

## The Advocacy Center Welcomes Intern

**Victoria Makofske**,  
a graduate student in Roberts Wesleyan College Masters of Social Work program, is interning in The Advocacy Center's Service Coordination Department. Victoria will be interning until May 2012.



## Special Education Advocacy Series for Professionals

*Five-Part Series Ideal for Service Coordinators, Advocates, Attorneys, Social Workers & Transition Specialists*

All sessions are Wednesdays, 1-5 pm, at The Advocacy Center, 590 South Avenue, Rochester, NY 14620

**Choose one or more sessions:**

**Session One**  
**Introduction to Special Education Laws and Regulations**  
Wednesday, October 5, 2011

■ ■ ■  
**Session Two**  
**Evaluations and IEPs**  
Wednesday, October 19, 2011

■ ■ ■  
**Session Three**  
**Working Effectively with Families**  
Wednesday, November 2, 2011

■ ■ ■  
**Session Four**  
**Behavioral Issues and Transition Planning**  
Wednesday, November 16, 2011

■ ■ ■  
**Session Five**  
**Evaluating Options and Advocating Effectively**  
Wednesday, December 7, 2011

For complete session descriptions and registration, please see [http://www.advocacycenter.com/pdf/2011\\_fall\\_professionals\\_series.pdf](http://www.advocacycenter.com/pdf/2011_fall_professionals_series.pdf)

To register, please email [registration@advocacycenter.com](mailto:registration@advocacycenter.com) or call our registration line at (585) 546-1700 ext. 399.

# Advocacy Center News

## Educational Outreach to Hispanic/Latino Communities

September 30, 2011

Dear Friends,

The Advocacy Center's vision is *Creating a World that Works for Everyone*. Our connection to the community is vital. We recognize and value the importance of building strong relationships with families, community agencies, local organizations, and schools so that together we can create a world that works for everyone.

The purpose of this letter is to reach out to form partnerships in building effective family and school collaborations to improve the educational success of students who have special education needs. We are seeking to expand our collaborative relationships to meet the needs of our Hispanic/Latino communities.

We are offering Spanish workshops which are designed to educate and empower parents to become involved in their children's education in a meaningful way. The Advocacy Center provides the training on-site for local organizations and schools. These workshops are available free of charge to parents. Do you work with families who might benefit from our services? Are you a family member who is interested in gaining more information and knowledge about how to work better with your child's school?

If you would like more information about our services or workshops, please feel free to contact me at (585) 546-1700 ext. 227.

Sincerely,

*Maritza Cubi*

Maritza Cubi

Bilingual Parent Education Specialist



Maritza Cubi recently completed the Latino Leadership Development Program, sponsored by the United Way of Greater Rochester.

**Congratulations Maritza!**

### Workshops currently offered by The Advocacy Center in Spanish:

- Agency Overview
- Advocacy Steps 101
- Advocating for Children with
  - Medical Issues: Getting Organized
  - Committee on Special Education Process: an Overview
- Bullying: Intervention Strategies for Parents and Professionals
- Communication: Effective Strategies
- Developing a Vision
- Individualized Education Programs:
  - The Essentials
- Special Education: Spanish Overview
- Promoting Graduation
- Bilingual Program: An Overview

Please note that other workshops may be developed to meet your particular needs. For further information please contact Maritza at (585)546-1700 or cubi@advocacycenter.com. To register for a workshop, please call our registration line at (585) 546-1700, ext 399. Or visit [www.advocacycenter.com](http://www.advocacycenter.com).

## LEGISLATIVE UPDATE

### Skills and Achievement Credential to Replace IEP Diploma - Public Comment Due November 21

#### Public Comment Requested

Public Comment - Proposed Amendment of Sections 100.5, 100.6, 100.9 and 200.5

The proposed amendment of sections 100.5, 100.6, 100.9 and 200.5 of the Regulations of the Commissioner of Education would repeal the individualized education program (IEP) diploma for students with disabilities upon expiration of the 2012-13 school year and, beginning with the 2013-14 school year, establish a Skills and Achievement Commencement Credential only for students with the most significant cognitive disabilities who have taken the New York State

Alternate Assessment and who are not eligible for a regular diploma.

The proposed amendment was discussed at the September 12-13, 2011 Board of Regents meeting. It is anticipated that the proposed amendment will be submitted for adoption at the January 2012 Board of Regents meeting with a proposed effective date of February 1, 2012. A Notice of Proposed Rule Making will be published in the New York State Register on October 5, 2011.

**Written comments on the proposed amendment will be accepted for 45-days after its October 5, 2011 publication in the New York State Register (must be received**

**by November 21, 2011)** and may be submitted to: New York State Education Department, P-12: Office of Special Education, 89 Washington Avenue, Room 309 EB, Albany, New York 12234, Attention: Skills and Achievement Commencement Credential. Comments may also be faxed to 518-473-5387 or emailed to [spedpubliccomment@mail.nysed.gov](mailto:spedpubliccomment@mail.nysed.gov). We request that written public comment regarding the proposed regulations be provided using the Public Comment Submission Sheet.

A copy of the proposed amendment may be accessed at <http://www.p12.nysed.gov/specialed/comment/terms-alternatecredential.htm>.

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saw anyone with a disability being teased, he would stand up for that person. "I want to make it easier for someone who has a disability."

15-year old Samantha commented that "It is so great that these devices are used to help others talk with us. It helps people communicate independently."

14-year old Andrew, "Wow these communications devices really do work, they aren't pretend, and they really do help people... Cool!"

By the end of the 3-hour workshop, all participants expressed a heightened awareness and acceptance of individuals with disabilities as well as a greater interest in learning more:

17-year old Kathleen stated that "With the right tools and support, people with disabilities can have independent lives."

16-year old Andrea observed "Everyone should be treated with good manners, including people with disabilities."

17-year old Jacob, a self-advocate, stated quietly, "I should be respected."

The youth will be invited to volunteer at a future Disability Awareness Day offered to area schools by The Advocacy Center.

*Disability awareness activities are designed to demonstrate communication, sensory, mobility, and fine motor challenges for individuals with disabilities. To arrange for a Disability Awareness workshop, please contact Public Education Coordinator Colleen Brown, 546-1700 ext. 267.*

### Helping Your Child Face Fears and Anxieties

**Saturday, October 15, 2011  
at 10:30 am,**

Pittsford Library, Fisher Room,  
24 State St., Pittsford, NY 14534

An educational workshop presented by the Tourette Syndrome Association, Greater Rochester and the Finger Lakes Chapter

Presented by Linda Bloch, Ph.D.,  
community psychologist

Annual Meeting will follow  
presentation.

Please RSVP by calling  
(585) 752-6190 or see  
[www.touretterochester.org](http://www.touretterochester.org)



# Siblings

Is your outlook on life different from your friends' outlook on life? How?

*"Yes, because I know that not everything is perfect – and that has made me a stronger person..."*

- From *The Sibling Slam Book*, edited by Don Meyer, Woodbine House, 2005



Shayla and Aaron on Aaron's 21<sup>st</sup> birthday

By Shayla Norton

## When I look at him, I see:

- a warm soul
- an incredible sense of humor
- someone who loves his DV-R
- an avid Cleveland Browns fan
- a person who has won his Fantasy Football league more than once
- a Batman fan
- someone whose favorite color is orange
- a Food Network fanatic
- someone who loves pineapple
- my hero
- my little brother

*I love you, Aaron!*



John and Jillian Arrington

## John

By Jillian Arrington

John is always so happy and when he's happy it makes me feel happy. Some of his favorite things to do:

Go on vacation, swimming, shopping for fans, singing, going to Roseland Water Park and going for car rides. He especially likes driving over bridges and train tracks. John does not like loud noises, dogs barking, and thunder storms. He is a caring and loving brother. Some of my favorite things about John is his smile and he is really funny. Some of my least favorite things about John is when he moves stuff in my room and I can't find things. Sometimes he likes to take down my posters on my wall. Even though he does these things I still and always will love him.

# Sister's Letter of Thanks leads to Self Discovery

By Sandy (Hise) Pray, 4th grade teacher, State Road Elementary School.

Sometimes it's hard to believe that it has already been twenty five years since, as a college freshman, I wrote an open letter to the Greater Rochester Spina Bifida Association thanking my sister for being who she was. I think it began as an idea for a cheap (er.. free) birthday present for her, but ended up being more a realization to myself just how lucky I was to have her in my life.

\*\*\*\*\*

You see, it wasn't until I went to college that I truly appreciated having a sister with a disability. Among many other reasons, to have a simple crush on a guy in my Psychology class was the classic light bulb over the head moment. One of my friends seemed astonished that I could even consider him to be cute. "But he's in a wheelchair!" was her first reaction. Wow. Really? Suddenly, a lifetime of hospital visits, cancelled family vacations, and endless reminders to "keep your things off the floor so Jackie won't roll over them", became invaluable, memories to treasure as defining moments in creating ME, who I am today.

\*\*\*\*\*

Fast forward several years and I introduced my family to a new boyfriend. He clearly had potential when he sat at Jackie's hospital bedside and told her to stop complaining about the food because he loved it himself. He then proceeded to eat what she wouldn't on her dinner tray. It was as simple as that. I knew I was going to marry this man. When we began planning our wedding, Mike and I selected our photographer carefully, making sure that we were confident in his ability to frame wheelchairs in the pictures. Even our reception hall was selected for its layout, and our house had only a few steps that we could easily pull her chair up. It was just something you do. That's how it is when you have a sister who uses a wheelchair.

When Jackie had a stroke shortly after the birth of my first son, her move to Monroe Community Hospital brought new opportunities for her, and also several years of family gatherings in the cafeteria or playground where she could be included. My son Darwin's baptism party was held in our garage where her wheelchair would fit. My husband was mortified



but I knew then that it isn't the place that mattered, it was being together- you don't exclude family from anything. My son had five great years of knowing his aunt before she passed on but he'll always remember visiting her. He'll always remember her at family gatherings and our Sunday treks up to see her.

\*\*\*\*\*

Life isn't always easy when you have a sibling with a disability. But if you can get past the moments of chaos, the times when you think that life can't do anything other than "stink", you realize that you are a stronger, better person for having him/her in your life. This summer, a counselor at Cub Scout camp was enraged that another teenager had made a joke that was offensive to people with Down Syndrome. "My sister has it, and he doesn't know what he's talking about!" I reminded him that this other person wasn't as lucky as we are- he will have to be taught how to see people for who they are. We've lived alongside people who teach us that lesson every day of our lives. We do things, say things, and live life without even a moment of hesitation for the love of our family. Others aren't so lucky.

I wonder if this will be that counselor's defining moment of life, as I had mine so many years ago.

\*\*\*\*\*

As my nine year old Noah enters the room while I finish this, he adds, "I know it was hard having a sister like yours. You missed homework because of her hospital times and you had to miss some fun stuff because of her having trouble. BUT....one great thing about having a sister in a wheelchair is that you always got to ride the elevator. You never have to go up/down the steps!" You know, he's right- I do love those elevators!

## Megan: Different in a Special Way

By: Emily Overfield, ALMOST 16  
about sister Megan Overfield, age 14

*Megan is very special to me,  
but not like a typical sibling.  
She is special in a different way,  
because she is different  
in a special way.*

*When Megan sees me for the  
first time each day,  
she always has a story to tell me  
in her own special Megan way.  
I love her for that, and I know  
she loves me, too.*

*Megan's bright, shining eyes  
and special way of talking to me,  
tell me that she is okay  
the way she is,  
even though she is so fragile.*

*Megan brings me joy  
with her smiles and laughter,  
yet she brings me fear,  
because I worry about her health.*

*If Megan was not my sister,  
my life would not be the same.  
She has changed me for the better  
because she is different  
in a special way.*



Emily and Megan Overfield

## Brother Reflects on Power of Communication

By James Traylor, Agency Director, SpecialCare  
Planning Team, Financial Architects

Over the past few months my sister Nathalie has mastered the art of "texting." Despite difficulties with fine motor skills, Nathalie can deftly maneuver a cell phone key pad and often sends loving, lighthearted messages to me and my middle sister Emily. Though her vocabulary may be limited, Nathalie almost always voices her true feelings. Conversations often revolve around: who is better at Guitar Hero, the latest Justin Bieber gossip or could she please kidnap my girlfriend's cat? Nevertheless, Nathalie clearly expresses how she feels.

As siblings, Emily and I have struggled to communicate our feelings about growing up with Nathalie. The first feelings were of frustration and anger. Why can't we go on vacation like our friends? Why do Mom and Dad never have time for us? Why can't Nathalie do this or do that? After this came feelings of embarrassment and resentment: tantrums at the grocery store, questions from friends and family, why isn't she like other kids?

As we grew up, Emily and I came to accept both Nathalie and our new family dynamic. Emily volunteered at Special Olympics; I taught a swim class for children with special needs. Over time our perspective changed so that eventually life with Nathalie was the only life we knew.

In retrospect, there were many moments when my family could have benefited from communicating more about Nathalie. I cannot emphasize how imperative it is to talk about feelings of frustration before they develop into resentment. It is important to focus on the fact that there are other families with children living with a disability. At some point the family needs to discuss future plans and whether a sibling may want to become a future caregiver.

It is interesting how growing up with a sibling with special needs changes your entire path in life. Professionally I help families with financial planning for their child with disabilities. My sister Emily has become a nurse in a pediatric cardiology unit that often works with children born with Down syndrome.

After 16 years, our communication with both Nathalie and about Nathalie is improving. The advent of social media, cell phones, iPads, etc. make communication much easier. Nathalie has even taken the liberty of communicating directly with my friends online. That said, I cannot emphasize the power of sitting down as a family and talking about both the family and the child with disabilities.

A little communication goes a long way.



Nathalie Traylor

## My Brother... *By Andrea Schaertel*

Nick is my name for you.  
 Inside the car, we watch movies together  
 during road trips.  
 Calls me when I'm out;  
 he likes to check up on me.  
 Has a huge heart...  
 and an even larger music collection.  
 One of the only people who never judges me.  
 Laughs at all of our jokes, even when  
 they're not funny.  
 Always congratulates me, and I know  
 he's proud of me.  
 Sisters can't get any luckier than this.



Nick and Andrea Schaertel

## News You Can Use!

### Area Sibling Resources

#### CDS Sib Shops

Siblings have the opportunity to learn and share through fun activities in a relaxed environment. This group meets for ten sessions per year at CDS' Wolf Life Transitions Center in Webster. The group meets two Saturdays per month from 10:00 am - noon. For more information or to register your child, please call Jackie Blake, Program Coordinator, at (585) 341-1031 or see <http://www.cdsunistel.org/ContactUs/>.

#### Spectrum Sibs

Spectrum Sibs is a Sibshop specifically for kids ages 8-12 who have a sibling with Autism Spectrum Disorder. Sibshops are a spirited mix of new games (designed to be unique, off-beat, and appealing to a wide ability range), new friends, and discussion activities.

Dates/Location: October 15; November 19; and January 21, 10am-12pm

Camp Arrowhead, 20 Arrowhead Road, Pittsford, NY, \$10 per child/per date  
 For further information, please email Gia Carroll at [gcarroll@unyfeat.org](mailto:gcarroll@unyfeat.org)



Joey and Jack Carroll

#### Allegany/Western Steuben Rural Health Network, Inc.

85 North Main Street, Suite 4, Wellsville, NY 14895, 585-593-5223

Contact: Helen Evans

A collaboration working together to provide workshops and activities, using the National Sibshop Project model, for siblings of children with disabilities.

#### Ontario ARC

2975 County Road, Canandaigua, NY 14424

Phone: 585-919-2053 Contact: Cyndee A. Jepsen

[www.ontarioarc.org](http://www.ontarioarc.org)

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## November is National Adoption Month

CHILDREN  
 AWAITING PARENTS **LIFT THE WAIT**

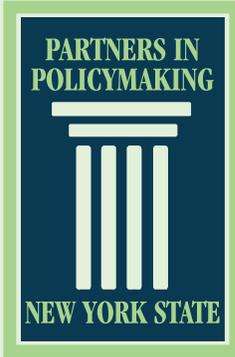


**Children never  
 outgrow the need  
 for parents.**

Thomas is a joyful, affectionate, happy young man! He loves music and books, going to the mall or the zoo, and socializing. Thomas likes to be around other kids and would do well in a family with pets. Thomas is a sweet, playful boy who will need ongoing care as he matures. He needs the unconditional love and permanency of a forever family to help him reach his full potential.

For more information, please contact Ilona Frederick, Child & Family Specialist, *Children Awaiting Parents*

595 Blossom Road - Suite 306  
 Rochester, New York 14610  
 P. 888.835.8802  
 F. 585.232.2634



**New York State Partners  
in Policymaking  
announces Class of 2012  
applications available  
on website:  
[www.nyspip.org](http://www.nyspip.org)**

**Applications Available for 2012 NYS  
Partners in Policymaking Program**

The New York State Partners in Policymaking program will be back again in 2012 with new content based on the successes experienced this year utilizing a blended interactive distance learning format.

The program, presented by Cornell University's Employment and Disability Institute (EDI) and The Advocacy Center of Rochester, is based on the national model of Partners in Policymaking. The learning format enables more individuals to avail themselves of this valuable training. The 2012 program will be an exciting combination of lessons learned from 2011 participants and new information.

The NYS Partners program continues to seek Partners graduates. If you are a Partners graduate, please register at the NYS Partners website.

For more information, contact:  
Jackie Yingling, NYS Partners  
Training Coordinator  
The Advocacy Center, Rochester, NY  
[Yingling@advocacycenter.com](mailto:Yingling@advocacycenter.com)

## News You Can Use! *continued from page 9*

### From Vanderbilt University **National Resources**

#### **Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD)**

This program promotes the successful aging of adults with intellectual and developmental disabilities in response to physical, cognitive, and environmental changes. It provides information on sibling roles and interventions in planning for transitions. [www.uic.edu/orgs/rrtcamr/index.html](http://www.uic.edu/orgs/rrtcamr/index.html).

#### **Sib Leadership Network (SLN)**

This project aims to provide siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. <http://sibleadership.blogspot.com>.

#### **Sibling Support Program**

This program is designed to support siblings of people with disabilities across the lifespan. The website provides information about statewide Sibshop support groups, workshops, national listservs, and general information about the needs and concerns of siblings. [www.siblingsupport.org](http://www.siblingsupport.org)

#### **SibNet Listserv—for adult siblings**

SibNet is the internet's first listserv for adult brothers and sisters of people with special health, developmental, and emotional needs. [www.siblingsupport.org/connect/the-sibnet-listserv](http://www.siblingsupport.org/connect/the-sibnet-listserv).

### **From the Editor**

I don't know exactly when our daughter Andrea realized that her brother had a disability. I suspect it was pretty early though. When she was nine years old, she announced that "Nick will live with me." I thought her biggest concern at the time was what color backpack to get. I didn't know what an impact Nick and his future had on her.

This issue is dedicated to siblings. A common thread runs throughout the sibling articles, poems, and photos – love and loyalty, understanding, friendship, and appreciation.

Our winter issue will focus on Financial Concerns, a topic of great importance to individuals with disabilities and their families.

*Maria Schaertel*

# Adult Siblings of Individuals with Disabilities

## TIPS AND RESOURCES FOR SIBLINGS

### Growing up with a Sibling with a Disability

Sibling relationships are often the longest-lasting relationships that children form. Like all siblings, they may or may not develop close emotional relationships depending on individual differences and circumstances. Regardless, a child's reaction to a sibling with a disability will have a lasting effect on siblings' self-esteem and emotional development.

### General Well-Being of Siblings

According to reports from the National Adult Sibling study, overall, siblings of adults with disabilities are doing very well. Siblings report that, as a group, they spend a fair amount of time with, feel very affectionate and close to, and have benefited greatly from their brother/sister with disabilities. Most siblings report that their physical health is either very good or excellent. Only a small percentage of siblings report being or having been depressed or blue.

### What Concerns Adult Siblings?

Because science and self-determination have so successfully contributed to the lengthened lifespan of people with disabilities, many questions arise for siblings about what the future will hold. Who will assist the sibling with a disability when the parents are no longer able to do so? Where will the brother or the sister with a disability live? How can typically developing siblings find their way through a maze of services that continually changes?

When parents involve siblings in the practical everyday planning issues and in the futures planning process for the sibling with a disability, siblings have higher confidence levels and feel more prepared to face future challenges in their adult relationships with their brother or sister. Get involved and be prepared. While families might face complicated and challenging issues, siblings who have a brother or a sister with a disability often have well-developed coping skills and often are highly proficient in finding new and innovative service options.

### Planning for the Future

Ideally, planning for the future has been a process in which all family members have been involved. Planning ensures that families are prepared to handle adult transitions and are aware when and how services are provided. Adult transitions may include: The transition from school services to adult services; moving out of the family home; aging issues, including health and health care; marriage and children; and grief issues, such as the loss of a parent.

To ensure preparedness, many families draft a "letter of intent." While not a legal document, this letter can include information about family members and their preferences for the future as well as information on medical histories and behavioral strategies. The letter can serve as a "roadmap" to developing legal and financial arrangements. A letter of intent might include:

- Family history (traditions and stories)
- Support network (friends and neighbors)
- Medical history (doctors and medications)
- Personal histories (capabilities and interests)
- History of activities (education, jobs, social, and volunteer)
- A list of what works (behavioral strategies and motivators)
- Service options in your state (housing and independence)
- Financial planning (estate and legal plans)

- Tip sheet from Vanderbilt Kennedy Center, Vanderbilt University. [www.kc.vanderbilt.edu](http://www.kc.vanderbilt.edu)



Rachael & Emma Yingling

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

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## Disability Employment Awareness Month

### Employment Options from OPWDD

The Office for People With Developmental Disabilities has developed many new services over the past several years. Recognizing that there is a lack of support available for people who may not need the high level of structure and support provided in traditional Day Habilitation and Prevocational settings, yet who lack the skills necessary to take the next step to Supported Employment (SEMP), new initiatives have been developed to help fill the gap. The Employment Training Program (ETP) and Enhanced Supported Employment Pilot are popular new options that both provide more support to individuals than traditional SEMP, enabling individuals to experience a longer transition period to adapt to workplace demands and to learn skills necessary to be successful. Additionally, the Finger Lakes DDSO, in partnership with the Institute for Innovative Transition, has been involved with development and implementation of Project SEARCH (a one-year job readiness training and internship program with local businesses to prepare students for work) and several college campus programs serving both students (18-21) and adults to learn work skills in a college setting. For further information, please contact Pat Barry at (585) 461-8826 or by email [pat.barry@opwdd.ny.gov](mailto:pat.barry@opwdd.ny.gov).



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