



disAbilities Celebration Connection

SPRING 2013

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Brothers and Sisters

Several times in these pages, I've spoken of my parents and myself, but not so much specifically about my brother, Philip. He was born in 1958 with profound cerebral palsy (CP), which was "caused" by my mother's Rh negative blood factor. This condition is easily prevented these days, but this wasn't the case in the middle of the last century.

His profound CP manifested in a nearly complete lack of muscle coordination. That is to say, he could not walk, talk, feed himself or perform any other of the activities that most of us take for granted.

But he was aware of his surroundings. He attended what was then called Lincolnia Center in Alexandria, where he was surrounded by the loving attention of caregivers and educators. He enjoyed being with his family, his face would cloud over with concern when my other brother and I fought, and he loved watching television, particularly, *Carol Burnett*, *Dick Van Dyke* and *I Love Lucy*. (remember this was the 60s and 70s) He had seen the shows enough times that he would laugh before the characters did something funny.

This might sound strange but over the 25 years of his life, I developed an empathic ability to ... kind of ... see the world through my brother's eyes. I knew when he was hungry or thirsty or uncomfortable; I knew when he needed to have his arms and legs, which were curling up due to atrophy, stretched out.

And I taught him to communicate, a little. He learned to stick his tongue out for 'Yes' and to keep it in for 'No.' I would ask him if he wanted a cookie, and get the

response for yes. Then I would ask if he wanted spinach, which he did not like. He would laugh and laugh and refuse to stick out his tongue.



Philip at age 9

During his time at Lincolnia Center and also, I think, at Central Fairfax Services, the teachers worked on this ability; eventually, they also discovered that he had some control over his thumb and they worked diligently with him using a picture board. He would press picture after picture until he got the answer he wanted.

Though I think of Philip everyday, I was reminded rather suddenly of his love of *I Love Lucy* when I was recently quite sick with bronchitis and spent nearly a week in bed. With my dog warming my feet, I indulged in non-stop reading, and watching old movies and TV shows. Then *I Love Lucy* came on. Maybe it was the fact that I was sick with an illness that regularly incapacitated me as a child, but all at once I was 12 again, Philip was 9, we were watching *I Love Lucy* together and he was laughing at her antics.

Philip passed away in 1984; the world has changed so much since then. I often think about how much he would have to say with the augmentative and alternative communication (AAC) devices now available, and I wonder how his laughter would sound today.

Laura Nelson, Editor



THANKS TO EVERYONE WHO HAS VISITED US ON FACEBOOK!

*d*isAbilities Celebration Connection and Celebrating Special Children can now be found at www.facebook.com/CelebratingSpecialChildrenInc

I am having so much fun working on the *Celebrating Special Children* facebook page. It's very exciting to open my home tab and see all the news stories that come right to me and that I can turn around and post with a click.

But several of my friends have patiently explained to me that I now need to work more on my personal facebook page and to figure out how to link the two pages! Ok-ok ... working on it.

I look forward every day to hearing from you!

Laura Nelson, Editor

WRITERS WANTED

*t*he *disAbilities Celebration Connection* quarterly newsletter currently has two wonderful writers, Carrie Smoot and Gregg Donaldson, who both contribute on a regular basis. Past issues have also included parents and professionals who have written about their battles won and lost, as well as their hopes and dreams for the future.



But there is always room for additional viewpoints and stories; I invite you to submit yours. Use the CONTACT US feature on the website's homepage to contact me for details. If your article is accepted for publication in the newsletter, I will edit it (after all, it is what I do!), and pay you \$100.

Happy writing!

Laura Nelson, Editor

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P.O. Box 11384
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Editor in Chief
Laura Nelson, M.Ed

Contributing Writers
Gregg Donaldson

Chairwoman of the Board
Bonita M. Pennino, M.S.

Questions? Comments? Please use the CONTACT US form at www.celebratingspecialchildren.org



Partners in Policymaking

The Commonwealth's Developmental Disabilities Council

Mission

To create a Commonwealth that advances opportunities for independence, personal decision-making and full participation in community life for individuals with developmental and other disabilities.

Vision

Virginians with developmental disabilities direct their own lives and choose how they live, learn, work, and play.

Become an Effective Advocate!

People with developmental disabilities or parents of young children with developmental disabilities are eligible to apply for Partners in Policymaking (PIP). The Partners program requires a substantial commitment of time, motivation and energy. Individuals participating in the program attend advocacy training, resource development and skill building workshops one weekend a month for eight months.

There is no cost to participate in the program. The Virginia Board for People with Disabilities (VBPD) supports participants by paying for transportation, meals, respite care, and lodging during training sessions.

Highly Motivated Virginians Encouraged to Apply

Individuals who are not already involved in advocacy organizations are especially encouraged to apply for the Partners program. Partners are chosen through a competitive application process administered statewide. Each applicant submits an application form and three letters of recommendation. The deadline is April 30, 2013 at 5:00 p.m. Participants are selected and notified in the month of July for the class beginning in the fall. Each session begins Friday afternoon and concludes late Saturday afternoon. **If accepted, attendance and participation in all eight training sessions (September 2013-May 2014) is required.**

Benefits:

- ▶ Get connected, speak up and out, educate, and communicate—on inclusion, quality education, accessible housing, and supported employment for people with developmental disabilities
- ▶ Build positive relationships with families, schools, employers, elected officials
- ▶ Learn how to impact local, state, and national policies through advocacy and awareness
- ▶ Improve the lives of people with disabilities in your local community and across Virginia
- ▶ Understand the strategies used to support people with developmental disabilities in their own homes across the life span
- ▶ Gain exposure to best practices, new philosophies, and current trends from national speakers and presenters

Applications Available Online—Apply Early!

Deadline April 30, 2013 at 5:00 p.m.

We strongly encourage electronic submission of application materials. To apply, please download the application at www.vaboard.org.

Contact Teri Barker-Morgan at VBPD with your questions. 1-800-846-4464 (Voice/TTY) or 804-786-9381 or teri.barker@vbpd.virginia.gov





AUTISM SPEAKS®
It's time to listen.

Kids and Teens with Autism Vulnerable to Video Game Addiction

Date: April 19, 2013: Thanks to Autism Speaks for this page.

www.autismspeaks.org/news

Parents and autism therapists have long noticed that many children and teens with autism become deeply engaged with video games and other forms of screen-based media. Indeed, many therapists and “app” makers design autism-friendly video games around this tendency.

Two new studies suggest that caution may be warranted.

“We found that children with ASD spent much more time playing video games than typically developing children, and they are much more likely to develop problematic or addictive patterns of video game play,” says University of Missouri psychologist Micah Mazurek, Ph.D.

The lead author of both studies, Dr. Mazurek is a co-investigator at the university’s Thompson Center, one of 17 sites in Autism Speaks Autism Treatment Network.

In one study, Dr. Mazurek looked at time spent on TV, video games and social media in children ages 8 to 18. She compared the habits of 202 participants with autism spectrum disorder (ASD) to those of 170 typically developing siblings. Those with ASD spent over 60 percent more time playing video games and watching TV than all non-screen activities combined. Boys with autism spent an average of 2.4 hours a day playing video games.

Girls with autism spent an average of 1.8 hours. By contrast, their typically developing brothers spent 1.6 hours playing video games; the sisters, less than an hour. The children with autism spent relatively little time using social media.



Participants also completed the “Problem Video Game Playing Test,” which assesses behavioral addiction to video games. Compared to their typically developing siblings, the children and teens with autism had higher levels of problematic, or addictive, video game use. Related behaviors include getting angry when interrupted from games, having trouble stopping game play when necessary and generally spending more time with games than with friends and family.

“Parents need to be aware that, although video games are especially reinforcing for children with ASD, children with ASD may have

problems disengaging from these games,” Dr. Mazurek says.

In another study, Dr. Mazurek tracked the behavior of 169 boys with ASD. She found an association between excessive video game use and increased oppositional behaviors.

Such behaviors include arguing, refusing to follow directions and aggression. However, an association does not prove that one causes the other, Dr. Mazurek cautions. She plans to pursue further study to clarify her findings.

On the positive side, video games show promise for helping individuals with ASD overcome social and communication challenges. “Using screen-based technologies, communication and social skills could be taught and reinforced right away,” Dr. Mazurek says.

“However, more research is needed to determine whether the skills children with ASD might learn in virtual reality environments would translate into actual social interactions.”

“Video games can be useful for teaching social skills and other behaviors,” agrees Autism Speaks Senior Vice President for Scientific Affairs, Andy Shih, Ph.D. “But we need to be sure that technology use is balanced with experience in the real world.” ■

Camp Choices and Options:

. . . Asking the right questions

By Carrie Smoot

Editor's note: This checklist first appeared in the hard copy of *Celebrating Special Children* in 2005. It accompanied an article that profiled several camps. While the information for those camps is out of date, it seemed to us that the checklist below will still be useful when looking for a summer recreational opportunity for your child. . . or for yourself!



Photo courtesy of Cerebral Palsy of Mideast Wisconsin

Along with the basics of location, cost, dates and times held, age requirements and whether the camp is a day or residential program, here are some important questions to keep in mind if you are looking for a special needs camp for your son or daughter, or perhaps, yourself.

Basic Information

- Is the camp accredited by the ACA (American Camping Association) and/or is it accredited or certified by other agencies?
- Is this a specialized or cross-disability camp?
- What is a typical day's program?
- What are the ages and range of abilities/disabilities of the campers?
- How many years has the camp been in operation as a special needs camp?
- Are camp scholarships available through the camp or a local disability organization?
- Are all areas that make up the facilities — playground, gym, fields, etc. — safe and totally accessible to your child?
- Is transportation with a lift available if necessary? What is the cost?
- Is there an open house to attend or a video of the camp available to view?
- Does the camp focus on one area such as language or reading remediation, motor skills development, therapeutic riding, adapted aquatics, etc.?
- If there is a wide range of developmental levels within a group, is there activity choice in a typical day's program?

NOTES

Important Procedures

- Are parents asked for extensive information about their child's needs, and contacted if there is a concern?
- Are parents encouraged to discuss what works best in behavior and discipline for their child?
- Does the camp director request written permission for contact with the child's teachers or therapists before camp begins?
- How are needs such as medication or restriction of activities handled?
- What safety, medical and emergency procedures are in place?
- If a child needs adaptive equipment, such as positioning equipment, will it be available at the camp for your child's use during camp hours?
- What equipment/clothing/supplies must you provide?

NOTES

Trained and Experienced Staff

- What is the ratio of campers with mild, moderate and severe disabilities to the junior and senior staff?
- What is the specialized background of the director, assistant director and program coordinator?
- What percentage of the staff are senior counselors who have several years experience working in a special needs camp?
- What specialized training have the staff members had prior to camp?

continued next page

- What type of medical personnel are present or on call during camp hours?

NOTES

For Programs with Aquatics

- Is the pool area safe and totally accessible, with a lift if necessary?
- Is the aquatics program recreational, instructional or therapeutic?
- Has the aquatics staff had specific training in adapted aquatics?

NOTES

Special Needs Residential Camps:

Additional Questions

- How are campers grouped for sleeping?
- What is the ratio of campers to senior counselors in the cabin or dorm?
- Does the staff member who handles the cabin on the counselor's day off have other times to get to know the campers?
- How are diet restrictions handled and what is a typical day's menu?
- How does the staff deal with homesickness? Can the campers call home?
- Are visits and telephone calls to campers from parents permitted?

NOTES

Looking for an Inclusive Camp

If you are considering an inclusive regular camp for your child with disabilities, you may want to think about the above questions as well as:

- Would your child be safe and healthy in a regular camp?
- Does your child enjoy being with other children without disabilities?
- Has your child been integrated in school, play or other recreational settings?
- What areas other than academics does his/her disability affect?
- Can your child make his/her needs and wants known?
- Is your child's behavior, social, and motor skills strong enough to limit frustration? How does your son or daughter handle frustration/ failure/ discipline?
- Does your child wander or even run away when he or she is out of your sight for even a single second?
- What do you want your son or daughter to get out of camp?
- Is the staff willing to accept help if needed to include your child in all activities?
- If your child is old enough to discuss the possibilities, does he/she have a strong preference for one type of camp over the other?

NOTES

In addition to these questions, you will want to ask other questions specific to your child's individual special needs.



Photo courtesy of Camp Easter Seals - UCP

CAMP LOCATOR RESOURCES

Check out the *Camps and Recreational Opportunities Section* under the **Community Resources** tab of the CSC website:
www.celebratingspecialchildren.org/main/community-resources

- **ACA Virginia**
www.acavirginiascamps.org
- **Easter Seals**
www.easterseals.com
- **Kids /Teen Summer Camps**
www.allensguide.com
- **Nichcy Camps for Children with Disabilities**
www.nichcy.org/publications/camps

Josh Blue . . .

Comedian, Painter & Athlete

by Gregg Donaldson

Editor's Note: I saw Josh Blue on Comedy Central one morning recently, and asked Gregg to write an article about him. Clearly, great minds think alike because he had already written one in 2007 for the Kennedy Center's Open Stages newsletter. This is a slightly revised reprint of that article. See reprint permission below.



Photo courtesy of Comedy Central

Josh Blue is a rising comedy star, who first appeared on Comedy Central's *Mind of Mencia*, before winning Best Comic on "Last Comic Standing-4," in the summer of 2006. He has also performed on the Ellen DeGeneres Show, and his DVD, *Josh Blue: 7 More Days in the Tank*, was shown in 220 movie theaters across the country. The DVD and his CD, *One Bad Arm* are sold through his website www.JoshBlue.com.

Opening Stages (now defunct - see note below) caught up with the Denver, Colorado native as he was traveling across the country, performing his comic routine at various colleges and other venues.

Donaldson: What are the different fields you work in?

Blue: I'm a stand up comic, painter and an athlete on the U.S. Paralympics Soccer team. I play as a striker, which is the forward position. I've been on the team for [many] years.

Donaldson: What drives you to be a comedian?

Blue: General insanity. Comedy works better for me than homicide or drumming for getting groupies.

Donaldson: What is your disability?

Blue: I have cerebral palsy. It affects my right side. In fact, my right hand has become a sign language interpreter, and I'm not even aware of it.

Donaldson: What are some of your most notable professional accomplishments?

Blue: Definitely winning *Last Comic Standing*. Also in 2004,

being part of the Las Vegas Comedy Festival, and becoming the grand prize winner of the Royal Flush Comedy Competition and earning \$10,000. Another highlight came with my art, when I had my own showing a couple years ago.

Donaldson: How did you become a contestant on "Last Comic Standing?"

Blue: I waited in line with a lot of funny people and a lot of interesting people.

Donaldson: How do you put together a routine?

Blue: I don't really do that too much. I have an idea of where I want to go. And once I get on stage, I feel out the audience and see what they like and don't like and go from there.

Donaldson: Does having a disability contribute to your comic perspective?

Blue: I always thought I was funny, but, if I didn't have a disability, I would just be another goofy white guy.

Donaldson: Do you ever use your disability to get laughs?

Blue: Yes. I talk about having a disability. I don't think I'm selling out. It's what everyone is already thinking: I'm just saying it. If I make the joke, it makes other people feel pretty dumb, if they make the same joke. You can't beat me, if I'm already there.

Donaldson: Can you explain that a little more?

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Note: Opening Stages [was] a newsletter produced by the John F. Kennedy Center for the Performing Arts at <http://www.kennedy-center.org>. The producer [was] Betty Siegel, editor [was] Paul Kahn.

See also www.kennedy-center.org/text/accessibility/opening_stages

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Blue: I've developed a "reverse teasing" style of comedy. I love making fun of you, making fun of me. For example, with CP some people perceive you to have a mental disability as well as a physical one. So, in my routine, I say, people come to me and ask, in a slow tone, "How- are- you bud-dy?" I answer in a palsy voice, "Fi-ne." Then, as they walk away, I may add, "I want to get laid," leaving them puzzled and wondering, "Did I really hear what I thought I heard?"

Donaldson: What do you think about movies that make fun of disability?

Blue: I don't really care, if it's intelligently done. If it's just a cheap laugh, it's lame.

Donaldson: On your DVD you said you worked at a zoo in Kenya? What did you do, and did it relate to your work in comedy?

Blue: I watered animals, fed them, hosed them down when they'd let me, scrubbed out their pens, danced jigs for the hyenas and stayed out of paw's reach of the lions' cages. It's pretty funny when a zoo full of animals is staring at YOU. But, no, I wasn't doing comedy then. It's like when your dad makes you change the oil blindfolded and says it's building character.

Donaldson: What have been the greatest rewards of your comedy career?

Blue: I love performing in front of crowds, making people laugh and traveling around the country. The only downside is

I don't like to fly. Man wasn't meant to be 37,000 feet in the air everyday.

Donaldson: What does it take to succeed in comedy?

Blue: You have to have talent, timing and develop your own style.

Donaldson: What advice would you give to other people with disabilities who want to pursue a career in comedy?

Blue: The most important is to watch other comics. Find out works and what doesn't and go to open mic nights.

Donaldson: What other comedians do you admire?

Blue: Chris Rock, Ellen DeGeneres, Dave Chapelle and Carlos Mencia are all people I look up to. They have all found their niche and found a way to beat the hell out of it.

Donaldson: What's next for you?

Blue: I hope to continue doing comedy and travel. I want to do TV and movies, do a show with Chris Rock at the Apollo, propose to Katie Holmes on top of the Eiffel Tower. And I want to compete with my teammates in soccer for the 2008 Paralympics Games.* ■

Gregg J. Donaldson is a freelance writer/editor based in Washington, D.C., as well as a published poet. His articles range from disability, entertainment profiles, technology to author profiles. In his spare time he is also a self-proclaimed movie critic. Visit www.facebook.com/gregg.donaldson.9 or email him at gjdwriter@gmail.com.

Additional Info:

• *The team did not play in the 2008 games in Beijing. For more info, visit www.ussoccer.com/teams/other-programs/paralympic-soccer/about-the-team.aspx

• In addition to being able to see snippets of his comedy on regular YouTube, Blue also has his own You Tube channel www.youtube.com/joshbluetube

See www.JoshBlue.com for information about upcoming performances all over the U.S for the rest of 2013. Virginia venues:

Funny Bone- Virginia Beach
Fri July 26 - Sun July 28
Virginia Beach, VA

Goodnight's Comedy Club
Thu June 6 - Sat June 8
Raleigh, NC

Arlington Drafthouse
Fri October 25 - Sat October 26
Arlington, VA

It's kind of funny," says Blue, now 33. "I'd be the only disabled kid in the neighborhood playing football, and we're playing full contact, and I'd always manage to get open. If you've seen me run, the key is you have no idea where the hell I'm going. It's just very deceptive. You're like, 'Is he going left, or right or what the hell is that?' Next thing you know I'm wide open in the end zone and high stepping it.

From an interview on ESPAN Playbook Fandom:
http://espn.go.com/blog/playbook/fandom/tag/_/name/josh-blue

Siblings Need Support Too

By Laura Nelson

Editor's Note:

I wrote this article in 2004 for the hard copy of Celebrating Special Children. I was reminded of it as I wrote this month's editorial. It's reprinted here with revisions and updates.

In 1958, I became the three-year-old big sister of a little brother with profound cerebral palsy. Parents, naturally, have their own story of what it means to care for a child with severe disabilities, but a sibling has unique perspective. During the 25 years of my brother's life, I developed a thick skin, a fiercely protective nature and a strong sense of empathy. Some of my most eloquent childhood memories are of teaching my friends (and anyone else within earshot, including well-meaning but misguided grownups) not to make fun of, not to be afraid of, and most of all, not to pity my brothers or others like him.

I'd like to say that I was the perfect big sister to my brother, but of course I wasn't. For every time I chastised (and sometimes beat up) a neighborhood kid for using the word, "retard," there were times that I was resentful for having to put my own life on hold in deference to my brother's needs. For every time I was proud of my ability to be compassionate and wise beyond my years, there were times that I was jealous of the attention my brother received.

Many years later, as a young adult, I spent some time in therapy sorting out my feelings. It wasn't ever that I didn't love my brother; it wasn't necessarily that I wished to have a

"normal" family, but it would have been an immense relief to have had someone I could talk to at the time, someone who understood what I was feeling.



Camping 1968! from left to right: middle brother, our dog, me, Philip, and Mom

The world has changed a lot in past 45 years with regards to families with children with special needs. The Individuals with Disabilities Education Act (IDEA) promised that children with every type of disability have the right to be educated in a public school setting. Further, the concept of Inclusion advocates that these children be educated in neighborhood schools. But siblings of children with disabilities must also have the right be visible in the community, to have access to support and services. When I was a child, no such support paradigm existed. Now it does.

While searching the Internet for resources for this article, one word kept showing up again and again: Sibshops. In 1994, Paul H. Brookes Publishing Company published *Sibshops: Workshops for Siblings of Children with Special Needs*, written by Donald J. Meyer and Patricia F. Vadasy. These authors recognized what siblings have always known and what parents sometime overlook: siblings of children with special needs need to be able to share their thoughts, concerns and fears about their unique circumstances. Unlike their parents, who came to the situation as adults, siblings have been siblings all their lives and may very likely bear the responsibility of guardianship for their sibling after the parents are gone.

Excerpts from the Sibshops book offered insight into the thoughts and feelings of some of these children: "...I have a new friend, Tom. We have a lot of fun together. My problem is that when Tom is joking around, he will say things like, "Cut it out, you retard!" I hate it when he says that because my baby sister, Jamie, has Down Syndrome. How can I get him to stop using that word?" or "Just because my brother has a disability and I don't, my parents expect me to be Superkid. They expect me to get perfect grades in school. Does that seem fair to you?" and, "I always have to babysit for

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my sister. She has problems and my parents say I am the only one they can trust. I want to get a job after school but I'll feel bad if I leave them empty handed."

With these children and others like them in mind, Sibshops: Workshops for Sibling of Children with Special Needs, was created with five clearly defined goals:

- Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.
- Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.
- Sibshops will provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.
- Sibshops will provide siblings with an opportunity to learn more about the implications of their sibling's special needs.
- Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.

In order to meet these goals, Sibshops provides a very easy-to-follow format which can be used by

anyone. As the Sibling Support Project website states, "Originally developed for eight-to thirteen-year old siblings of children with developmental disabilities, the Sibshop model is easily adapted for slightly younger and older children. It has been adapted for brothers and sisters of children with other special needs, including cancer, hearing impairments, epilepsy, emotional disturbances, and HIV-positive status."

In addition, according to the book, "Any agency that serves families of children with special needs can sponsor a Sibshop provided it can financially support, properly staff the program, and attract sufficient numbers of participants. It's most effective if agencies work together to co-sponsor a local Sibshop. [The authors] have found that Sibshops are well within the reach and abilities of most communities. They are not expensive to run, and logistical are no more difficult to coordinate than other community-based programs for children, such as Scouts." Teachers, social workers, school guidance counselors and parents can all be facilitators of the workshop model. It's even possible that a local social services agency, school or church near you is already holding a Sibshop workshop. In Fairfax County, the public school system periodically provides sibshop workshops. Here are some of the comments of the participants: Hannah, a 10-year-old said, "The

best parts were being with other kids who know what it's like to have a "different" brother, cooking together, and just talking." We really appreciated the availability of this program." Parents, too, expressed appreciation of the opportunity to have their children attend a SibShop. One mother said, "Thank you so much for the opportunity for my children to attend the SibShop class. They have felt frustration over the behavior of their brother recently diagnosed with Asperger's. His reactions and behavior often caused them to feel embarrassed and out of step with their peers. Your class provided a safe place to explore their feelings and to put some concrete actions in place to deal with their feelings. This was a unique opportunity for them and we are so very grateful. Please encourage others to participate in this program as facilitators and as participants. Each will be rewarded." If you can't find a sibshop in your community, bring this article to the attention of someone at your school, church or social service agency. You can help your "other" kids get the support they need by helping to start a sibshops workshop in your community. ■

My thanks to Don Meyer, who, in 2004, gave me permission to quote information from this book and from the Sibling Support website.

Sibshop Resources

The Sibling Support Project

A national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns. Look for ways to connect to other sibs on this site, as well locations for Sibshops.

<http://www.siblingsupport.org>

The ARC's Information for Siblings

The role of sibling to a person with an intellectual and developmental disability (I/DD) is as complex as it is inspiring. Many at The Arc know firsthand what it is like to grow up with a family member with I/DD.

www.thearc.org/siblings

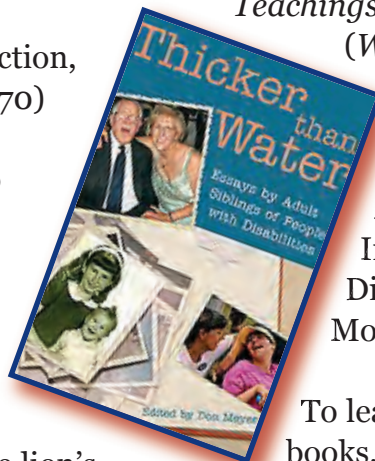
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Now available~

Thicker than Water: Essays by adult siblings of people with disabilities

In this thought-provoking essay collection, thirty-nine adult siblings (ages 20 to 70) reflect on how their lives have been indelibly shaped by their relationship with a brother or sister with special needs.

Edited by Don Meyer, *Thicker than Water* reveals both positive and negative aspects of growing up with someone who might have received the lion's share of his parents' attention or who now requires extra support as an adult. Authors include Rachel Simon (*Riding the Bus with My*



Sister), Mary McHugh (*Special Siblings*), Kate Strohm (*Being the Other One*), Veronica Chater (*Waiting for the Apocalypse*), Edgar-award winning author Nancy Werlin, filmmakers Jeff Daly (*Where's Molly?*), Jennifer Owensby (*The Teachings of Jon*), and Susan Hamovitch (*Without Apology*), Kim Keprios (Ex. Director of the Arc of the Great Twin Cities), Doreen Croser (Ex. Director of the American Association of Intellectual & Developmental Disabilities), disability activist Jeff Moyer and many others!

To learn more about this and similar books, visit The Sibling Support Project Store's Books about sibs and families at <http://astore.amazon.com/thesibsuppro-20>

Sibshop Facilitator Training

The only way to become a first-generation Sibshop facilitator is to attend a two-day Sibshop training. And adult sibs, parents, service providers, university students and others often join us for the first day for a lively and rewarding discussion of sibs' issues across the lifespan. We hope you can join us!



More trainings will be listed here as dates are confirmed, so check back often! Confirmed dates for upcoming Sibshop trainings in the United States:

May 10 & 11, 2013

Milwaukee, Wisconsin
Hosted by the Autism Society of Southeastern Wisconsin
Registration contact:
Emily Levine 414-988-1260
www.asew.org

September 27 & 28, 2013

Tucson, Arizona
Hosted by the Autism Society - Greater Tucson chapter
Registration contact:
(520) 324-3284 or (520) 770-1541
www.AutismSocietyGreaterTucson.org



Augmentative and Alternative Communication

Editor's Note:

Augmentative and Alternative Communication (AAC) refers to methods of communication that enhance (augment) or replace (alternative) conventional forms of expression. If that sounds a bit confusing, just consider that cool talking computer used by famed physicist Stephen Hawking as one example of AAC.

United States Society for Augmentative and Alternative Communication

☞ **United States Society for Augmentative and Alternative Communication**

National chapter of ISAAC, the International Society for Augmentative and Alternative Communication; organization dedicated to supporting the needs and desires of people who use AAC, as well as the family members, professionals, and manufacturers making up our community.

www.ussaac.org

☞ **Augmentative and Alternative Communication (AAC) Institute**

Organization dedicated to the most effective communication for people who rely on augmentative and alternative communication (AAC).

www.aac institute.org/index.html

☞ **American Speech-Language Hearing Association**

Works to ensure that all people with speech, language, and hearing disorders have access to quality services to help them communicate effectively.

www.asha.org/public/speech/disorders/AAC/

☞ **National Institute on Deafness and Other Communication Disorders (NIDCD)**

Conducts and supports research and research training in the normal and disordered processes of hearing, balance, smell, taste, voice, speech, and language.

www.nidcd.nih.gov/health/hearing/Pages/Assistive-Devices.aspx

☞ **Wikipedia page for Augmentative and alternative communication**

A very extensive history of AAC with many citations and notations.

http://en.wikipedia.org/wiki/Augmentative_and_alternative_communication

☞ **Camp Chatterbox**

Therapy camp for nonspeaking or severely speech-impaired children, ages 5 -15, who functionally use synthesized augmentative and alternative communication (AAC) devices.

New Jersey (*We don't normally list camps so far away but this one is unique.*)

www.campchatterbox.org/

☞ An internet search with the term “*using aac devices*” reveals many for-profit companies that make these devices.

2013 National Health Observances

Please visit <http://healthfinder.gov/NHO/nho.aspx?year=2013#top-of-page>
for a complete calendar of observances

Source: 2013 National Health Observances, National Health Information Center, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, Washington, DC.

MAY

Arthritis Awareness Month

Arthritis Foundation

www.arthritis.org/arthritis-awareness-month.php

Better Hearing and Speech Month

American Speech-Language-Hearing Association

www.asha.org/bhsm/

Mental Health Month

Mental Health America

www.mentalhealthamerica.net/go/may

National Asthma and Allergy Awareness Month

Asthma and Allergy Foundation of America

www.aafa.org/display.cfm?ID=5&Sub=105&Cont=457

National Celiac Disease Awareness Month

American Celiac Disease Alliance

www.americanceliac.org

5 –11 ~

Children's Mental Health Awareness Week

National Federation of Families for Children's Mental Health

www.ffcmh.org

12–18 ~

Food Allergy Awareness Week

Food Allergy & Anaphylaxis Network

www.foodallergy.org/section/food-allergy-awareness-week1

13–19 ~

National Stuttering Awareness Week

Stuttering Foundation of America

www.stutteringhelp.org

JUNE

1– JULY 4

Fireworks Safety Month

Prevent Blindness America

www.preventblindness.org/2013-prevent-blindness-america-eye-health-and-safety-observance-calendar

National Aphasia Awareness Month

National Aphasia Association

www.aphasia.org/congress_proclaim_naam08.html

19 ~

World Sickle Cell Day

African American Blood Drive and Bone Marrow Registry for Sickle Cell Disease Awareness

www.aablooddriveandmarrowregistry4sickle-cellawareness.webs.com/worldsicklecellday.htm

24 ~

Heat Safety Awareness Day

National Oceanic and Atmospheric Administration

National Weather Service

www.weather.gov/om/heat/index.shtml

JULY

Cord Blood Awareness Month

Parent's Guide to Cord Blood Foundation

www.parentsguidecordblood.org

Juvenile Arthritis Awareness Month

Arthritis Foundation

www.arthritis.org/ja-alliance-main.php

National Cleft & Craniofacial Awareness & Prevention Month

AmeriFace

www.nccapm.org/