



dis-Abilities Celebration Connection

FALL 2011

October is Disabilities Awareness Month

IN THIS ISSUE

Letter from Editor	1
Virginia Board for People With Disabilities	2
Publication Info.	3
Links I Love	4
Life with Aphasia	5
Commonwealth Community Trust	7
No More Secs!	8
Inclusive Schools Week	10
Life Without Barriers . . .	11



As some of you may know by now, I grew up in the '60s, '70s and '80s as the older sister of a brother with profound cerebral palsy. He lived at home with us for all of his 25 years and his well-being was of central importance in my life. Maybe not surprisingly, I have a strong memory of isolation. No families around us seemed to have a similar situation. My parents had to drive long distances to get access to services which were, indeed, few and far between.

My experiences with my brother and my family gave me an increased sense of compassion and empathy for those for whom daily activities are a challenge, as well as an acceptance of the fact that life simply is the way it is. It also gave me the ability to see victory in small accomplishments.

When I was growing up all those years ago, the idea of "disabilities awareness" was an unknown concept, at least from my point of view as a child. Now, many years later, it continues to amaze me that we as a society, are surrounded by the concept of "disabilities awareness."

You know how, when you buy a red car, suddenly you see red cars all over the place? Well, it's my impression that that is happening to our society. Everywhere we go, everyone we talk to has a story or knows someone who has a story about disabilities. This issue of *dis-abilities Celebration Connection* is devoted to disability awareness. We have included links to state and national organizations that work to increase disability awareness and what's more important, the full inclusion of people with disabilities into society, instead of what could be termed a 'parallel' inclusion. Several of the articles in this issue were written by and about people who refused to be relegated to second class status because of the disability issues in their lives.

These shared stories help bond the disability community, making it stronger and moving it forward. It gives me immense satisfaction to be a part of the Celebrating Special Children (CSC) organization, which participates in the conversation by disseminating information and helping to foster awareness so that people never again feel that sense of isolation that my family felt so many years ago.

Laura Nelson
Editor



Editor's note:

My sincere thanks to the Virginia Board for People with Disabilities (www.vaboard.org), which has the information below, with associated links, posted to its website. The Board serves as Virginia's Developmental Disabilities Planning Council, addressing the needs of people with developmental disabilities as established under the federal "Developmental Disabilities Assistance and Bill of Rights Act" and the state "Virginians with Disabilities Act". Since 1992, the Board has been an executive branch state agency located within the Secretariat of Health and Human Resources. The Board has autonomy over the use of its federal funding and the hiring of its staff.

The Board advises the Governor, the Secretary of Health and Human Resources, federal and state legislators, and other constituent groups on issues related to people with disabilities in Virginia. The Board's purpose is to engage in advocacy, capacity building, and systems change activities that contribute to a coordinated consumer and family centered, consumer and family directed, comprehensive system of services, individualized supports, and other forms of assistance that enable individuals with DD to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.

This is accomplished through outreach, training, technical assistance, supporting and educating communities, barrier elimination, system design/redesign, coalition development and citizen participation, informing policymakers, and demonstration of new approaches, services, and supports to community-based service delivery.

October Is Virginia Disability History and Awareness Month

During its 2009 session, the Virginia General Assembly adopted Senate Joint Resolution 321 designating October as Disability History and Awareness Month in Virginia. The resolution specifically cites four principles on which the Americans with Disabilities Act, and its predecessor the Virginians with Disabilities Act, are based: "inclusion, full participation, economic self-sufficiency, and equality of opportunity for all people with disabilities." It further cites the prevalence of disabilities among Virginians and their impact on individual citizens, their families and caregivers, and society in general. In passing the resolution, the General Assembly called upon the Governor "to encourage the people of the Commonwealth, including public schools, institutions of higher education, the business and corporate community, civic and advocacy organizations, the faith community, and other interested entities, through education and other appropriate activities, programs,

and events to promote and highlight Disability History and Awareness Month in Virginia."

In the resolution, the General Assembly also recognized the efforts of alumni of the Youth Leadership Forum (YLF), sponsored by the Virginia Board for People with Disabilities, whose advocacy efforts prompted the legislature's action. Following passage of the resolution, those YLF alumni, with support from parents, teachers, and the Virginia Board, the Partnership for People with Disabilities at Virginia Commonwealth University, the Virginia Department of Education's Division of Special Education and Student Services, and the Technical Assistance and Training Center at Radford University, developed a bank of resources to increase students' understanding and awareness and to support development of activities to commemorate Disability History and Awareness Month in their schools and communities.

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Links to those and other resources are provided below to encourage commemorative and educational activities all across the Commonwealth which will, in the words of the General Assembly's

resolution: "increase public awareness and respect for persons with disabilities, inform the public concerning their many contributions to society...and emphasize the abilities and rights of disabled persons." ■

Resources

- **October is Disability History & Awareness Month (document)**
www.vaboard.org/downloads/DisabilityHistoryAwarenessMonth.pdf
- **Virginia Center for Self-Advocacy: Disability History and Awareness Month Resources**
www.vcu.edu/partnership/C-SAL/disabilityawareness.htm
- **Partners in Time: A Self-Study Course Exploring Disability History from Ancient Times to Today**
www.partnersinpolicymaking.com/history
- **Disability Is Natural: People First Language**
www.disabilityisnatural.com
- **US Department of Justice: Americans with Disabilities Act Information and Technical Assistance**
www.ada.gov
- **Disability.gov: Connecting the Disability Community to Information & Opportunities**
www.disability.gov
- **US Dept. of Labor: Office of Employment Policy Resources**
www.dol.gov/odep
- **Partners in Policymaking Disability Resources**
www.partnersinpolicymaking.com/resources.html
- **American Association of People with Disabilities**
www.aapd.com
- **Disabled World: News and Information for the Disabled Community**
www.disabled-world.com
- **Disability Rights and Accommodations Quiz**
www.smith.edu/ods/announcements/quiz.php
- **Virginia's Disability Services System**
www.vaboard.org/assessment.htm



Look for the next issue of *dis-Abilities Celebration Connection* to be posted during the month of January, 2012. . Remember to send us story ideas, interesting links, and events. We can't do it without you!

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

Links I Love~

Additional links for Disability Awareness Month



- **William and Mary School of Education Training and Technical Assistance Center**

T/TAC staff provide a variety of request-based support services and assistance to educational professionals serving school-age students with mild and moderate disabilities or transition needs in Eastern Virginia.

<http://education.wm.edu/centers/ttac/news/virginia-disability-history-and-awareness-month.php>

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- **Colleges with Programs for Learning Disabled Students**

Almost all colleges and universities provide some level of services and/or accommodations for learning disabled students, as mandated by the Americans with Disabilities Act (ADA). The colleges and universities listed on this site go a step further...they offer programs, some quite comprehensive, designed to support students with learning disabilities.

www.college-scholarships.com/learning_disabilities.htm

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- **Project Forum**

Aim is to facilitate improved services to children and youth with disabilities by gathering and sharing information that supports changes to policy and practice at the national, state and local levels.

www.projectforum.org/index.cfm

- **National Disability Rights Network**

Serves a wide range of individuals with disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems.

www.ndrn.org

- **National Organization on Disability**

Advocates internationally and nationally for the mainstreaming and full participation of people with disabilities in all aspects of life.

www.nod.org

- **Council of Parent Attorneys and Advocates, Inc.**

Does not provide direct legal representation but ensures the availability and quality of legal and advocacy resources for parents of children with disabilities. Parents who are looking to find a special education attorney or a special education advocate may look up referrals in the COPAA Member Directory.

www.copaa.org

- **Virginia Office for Protection and Advocacy**

Protects individuals with mental illness or other disabilities from abuse, neglect, discrimination and other violations of their legal or human rights. Callers with problems targeted in VOPA's program priorities may also receive free advocacy services and/or free legal representation.

www.vopa.state.va.us

- **Wright's Law Advocacy and Law Libraries**

Based in Virginia, online source of articles, cases, newsletters, and other information about special education law and advocacy. Also presents conferences and trainings.

www.wrightslaw.com



Living Life with Aphasia - and Feeling Included

By Carrie Smoot

Chris, who lives in Baltimore, MD, enjoys traveling with her husband and spending time with their 27-year-old daughter, whom she describes as “a riot.” She says this while laughing. She likes a variety of activities—such as knitting, working in a greenhouse, learning Baltimore history, art, and music. The Canton Pub, near her home, is a favorite restaurant. “Everyone there is very friendly,” Chris says. “I feel welcome.”

Tackling Challenges

But Chris also tackles some big challenges when visiting restaurants, stores and other public places. Four years ago, Chris became one of the one million individuals in the United States who has aphasia, an acquired communication disorder. According to the National Aphasia Association (www.aphasia.org) in New York, NY, aphasia affects a person’s ability to speak and understand others. People who have aphasia have difficulty reading and writing. Most importantly, it does not affect intelligence. Many people have never heard of it. Anyone at any age can have aphasia. The most common cause is a stroke or other neurological disorder.

“I was in the hospital, and I fell flat on my face,” Chris recalls. “I wish I didn’t have aphasia.” Highly verbal, Chris often has to ask people to slow down their speech, to be patient, wait, and to use shorter words so that she can understand them better. She communicates by showing

people pictures of what she would like to do. A quiet environment also helps in understanding. When possible, she likes using Skype to talk with people over the phone so that she can see their expressions.

The Snyder Center for Aphasia Life Enhancement (SCALE)

The classes that Chris enjoys take place at Baltimore’s Snyder Center for Aphasia Life Enhancement—known as SCALE—two times a week. She and the other 39 Center members had the chance to tell local businesses about how they could better serve people with aphasia during awareness training sessions. The group also made picture menus and laminated cards with various pictorial directions on them that were specific to each type of business.

SCALE (www.scalebaltimore.org) began in 2008, according to executive director Denise McCall, who is also a speech-language pathologist. “Our mission is to improve the quality of life of people with aphasia and their families by educating the public about what aphasia is,” she says. “All too often, people with the condition are mistakenly thought to be drunk, having an intellectual disability, deaf, or on drugs—but it comprises difficulties in reading, writing, listening, and speaking. It is often said that aphasia is like a snowflake—every person is affected by it differently.”

McCall applauds the willingness of businesses to get involved. “The members have told them what works and what doesn’t—that they need increased lighting and signage, and so forth. The group is working on a DVD about the project now.

“The shoe store, for example, offers a line of Velcro shoes popular with stroke survivors,” McCall explains. “If you have hemiplegia, you can’t tie your shoes. Velcro is much safer and more convenient.”

McCall credits the generosity, warmth, and caring of the Snyder family for being the nonprofit’s greatest benefactors. “Howard’s brother, Andrew, and his wife Cherie Snyder have enthusiastically taken on that role,” says McCall. “Howard had a stroke 12 years ago, which left him with aphasia. The communication frustrations can cause a person to retreat or avoid difficult situations. The Snyders wanted Howard to maintain a happy and productive life, but there were no services around, so they decided to start the Center.”

SCALE is based on the life participation approach. “That means, regardless of your residual impairment, you must be in community,” says McCall. Several times a week, she and her staff work with the members on speech therapy, communication skills, and so on. In addition to the onsite greenhouse, they offer yoga classes and other activities.

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The Aphasia-Friendly Business Program

The Aphasia-Friendly Business Program, which began in January 2011, is about to be launched in select cities and states through the NAA. So far, the effort will expand to New York City, Long Island, Orlando, Nashville, Hayward, CA, Ohio and Kentucky.

"It's a win-win for people with aphasia, who shop as part of everyday life. For business owners, it's a way to attract more customers, serve everyone better by providing reasonable accommodations, and create a welcoming, community-oriented environment," says Ellayne Ganzfried, CCC-SLP, executive director of the NAA. "The aphasia-friendly business materials can also be useful to those that have other communication barriers, like not speaking English. As business owners and their staff are trained, they in turn can teach other people," she says.

"Our state partners in these areas indicated interest in starting programs," she says. The pilot program in Baltimore focused on a restaurant, a bank, a shoe store and a pharmacy—typical places near the Snyder Center that everyone would frequent. Each of these businesses received awards and recognition in June for their participation in the project. June is National Aphasia Awareness Month.

Ganzfried says that the NAA will track how well the programs are doing, and that they will post the names of the aphasia-friendly businesses on the website as the program gets underway.

It's also possible for someone with aphasia to improve over time, Ganzfried says. The NAA also offers a

communication card that someone with aphasia can use to facilitate communication with others. All they need to do is check off applicable items.

Business owners and employees have been profoundly changed by their involvement in the Aphasia-Friendly Business Program. Aaron Reinhart is the owner of Swallow in the Hollow, a well-known and popular local restaurant and bar in a 1940s-era building.

"We're near the Center, and a lot of the patrons would stop in after their classes to have a meal or a snack, and we began to notice familiar faces, and we got to know people," says Reinhart. "The Snyder Center approached me about attending their training. Up until then, I had no idea what aphasia was. I asked another of my managers to attend with me. What we learned there has really opened our eyes."

“. . . being aware of the needs of people with aphasia has led to better accommodations for those with other disabilities and unique needs.”

One of the first things Reinhart did after attending the training was to replace the antique towel racks in the bathroom with automatic ones. "Many stroke survivors have paralysis on their right side, and cannot use their hands easily, so it's much easier just to push a button."

The most important thing, he says, is patience. "Unfortunately, the restaurant business is often hurry-up-and-wait. For someone with aphasia, that means patience is in order. Give them a chance and some time to say what they need to say. Give them the

benefit of the doubt." Swallow in the Hollow also has picture menus on hand, but they haven't yet had to use them.

Some business owners have firsthand experience of aphasia in their families. "Stroke is a wake-up call," says Tija Jackson, Relationship Manager at M&T Bank. One of her relatives suffered a stroke. "You don't think about what stroke is until it happens to you and your family, and how it affects other people. It was a difficult time, but we all pulled through," she says.

M&T Bank is in the same building as the Snyder Center, so Jackson decided to attend the training as well so she could teach it to others in her department. She has also reached out to the marketing department to spread the word about the program.

"I've noticed in general that people are much more patient now with everyone—all the time, but especially around the first of the month—our busiest time," she says. Her pin and bracelet honoring those with aphasia are excellent conversation starters. Bank employees use laminated cards with basic money and banking tasks on them, like deposits and withdrawals.

"Where possible, people want to take care of certain tasks for themselves," says Jackson. "Patience is critical, because the more you try to hurry someone, the more flustered they become," she says. "You have to be aware of nonverbal cues as well."

Jackson says that being aware of the needs of people with aphasia has led to better accommodations for those with other disabilities and unique needs. "That's the 'wow' factor," she says. ■

Carrie Smoot is a Northern Virginia freelance writer.

Five Things to Consider When Setting Up a Special Needs Trust



by Joanne Marcus, MSW
Executive Director, Commonwealth Community Trust

1. Why establish a Trust

A Trust allows the Grantor, the person establishing the trust, the opportunity to create a trust that will enrich the quality of life of the beneficiary who is living with a disability. The recipient may be applying for or receiving Medicaid and Supplemental Security Income (SSI) and want to protect benefits that are crucial in providing medical care and income necessary for support. In order to qualify for these benefits, the individual can have no more than \$2,000 in cash assets. A monetary gift, settlement, or inheritance will disqualify the Beneficiary from receiving these benefits. A trust can be used, for example, to purchase a wheelchair, dental services, eye glasses, hearing aids, education, recreation, travel, transportation, furniture, electronic equipment and clothing.

Two Types of Trusts: Third Party Special Needs Trust and Self-Funded Pooled Disability Trust

The third party Special Needs Trust (SNT) is funded by a third party, usually a close family member, and can be coordinated with the family's estate plan. The SNT holds funds that the grantor leaves for the beneficiary's benefit.

The self-funded Pooled Disability Trust (PDT) is funded by the person with a disability, generally through an inheritance or personal injury award. This trust is sometimes referred to as a Medicaid payback trust as people who receive Medicaid will have to pay back the state for medical expenses incurred on their behalf with funds remaining in the trust after the death of the beneficiary.

2. Advantages of a Nonprofit Organization

The pooled trust program is administered by a nonprofit corporation and has the advantage of lower administrative costs and greater opportunity for investment potential. While the funds are pooled for investment purposes, individual sub-accounts are maintained and financial reports are provided. Staff are experienced and knowledgeable

about the needs of people with disabilities and the rules that will protect SSI and Medicaid. There is no minimum amount required to establish the trust.

3. Who to Call

Once you are ready to establish the trust, you can contact organizations like Commonwealth Community Trust (who can serve as the trustee) and the Special Needs Alliance (who can connect you with an estate planning attorney). Because the regulations are complex and constantly changing, it's important to select an attorney or nonprofit that specializes in these types of trusts.

4. Role of the Trustee

Both trusts require that a trustee be designated. The trustee manages and invests the funds for the trust and approves disbursements that are for the sole benefit of the beneficiary. The trustee is knowledgeable about government agencies providing benefits and staying abreast of changing regulations.

5. Role of the Advocate

An advocate is designated by the grantor (individual funding the trust) and is generally someone close to the beneficiary such as a family member, guardian, conservator, case worker, power of attorney or, depending on the nature of the disability the beneficiary. The advocate works closely with the trustee in submitting requests for disbursements that will maintain the quality of life for the beneficiary. The grantor can complete a set of instructions (forms are available to assist in this) indicating their vision for the trust. ■

Commonwealth Community Trust (CCT) is a national nonprofit organization established in 1990 by concerned citizens and parents of children with disabilities to provide an effective and affordable administration of third party Special Needs Trusts and self-funded Pooled Disability Trusts. For additional information, FAQ and trust documents visit www.commonwealthcommunitytrust.org or call 888-241-6039.





No More Secs!
Living, Laughing, & Loving
Despite Multiple Sclerosis

No More Secs!

Living, Laughing, & Loving Despite Multiple Sclerosis

By Carrie Smoot

As someone who has multiple sclerosis, Ann Pietrangelo of Winchester, VA, frequently answers questions from others with MS through Care2.com, one of the websites where she is a contributing writer on health-related issues.

"I get emails all the time from people who are also dealing with MS. I always preface my responses by saying that I'm not a doctor, and that they should seek out medical advice for their specific needs and situations," Pietrangelo says. "I can only share approaches that have worked for my husband, Jim, and me—lots of research, asking many, many questions and continuing to live life fully."

Pietrangelo was 44 when she was diagnosed with MS. Her relationship with Jim had just begun. The more Pietrangelo observed about the way her body felt, the Internet research they did, and their many questions led them on a round of doctor visits. A couple of times, she asked doctors point-blank: "Do I have MS?" Their suspicions were confirmed. Pietrangelo laments that she never got her "Marcus Welby moment" from caring doctors.

As she writes in her 2011 memoir, *No More Secs! Living, Laughing & Loving Despite Multiple Sclerosis*:

So that's it then. The door has closed on wishful thinking. All doubt is removed and the mystery is solved. I have multiple sclerosis. We can say it out loud now. It is no longer the mysterious stranger who we fear, but the positively identified culprit who is moving in with us, bag and baggage, to share our home and our future. We won't be strangers for long.

She asked herself: "Will I still be me?" The response is in her book:

Yes, I still look like me and, except for the foggy feeling from over-thinking the situation, I still feel like me. What else was I expecting?

As noted above, Pietrangelo wrote about her life experiences in *No More Secs! Living, Laughing & Loving Despite Multiple Sclerosis*. She comments, "A book on MS should be written from a regular person's perspective—like me—not just celebrities who have the disease," she says. "It lets people know that, hey, they are not alone." She notes that Montel Williams, Teri Garr and Annette Funicello have each written about their MS.

When taking a break from managing their web writing and design firm, WebCamp One, Pietrangelo and her husband enjoy the outdoors and the mountain views of their area. Most recently, they took a week-long road trip to visit their adult children. Other evenings are quiet. They spend time with their cat, Smokey, watch movies and munch on popcorn.

Pietrangelo points out that MS affects people differently. She has relapsing/remitting MS, which causes sudden and severe symptoms—weakness, dizziness, an inability to walk or move her arms, and vision loss. She says that for unknown reasons, it has been in remission since April 2010, and she doesn't know when it's going to show up again. "It's almost like I'll be saying, 'Oh, it's you again!' to a surprise visitor," Pietrangelo says, laughing.

MS came along at a time in Pietrangelo's life when she was hoping to finally be free of much of the stress she had been experiencing. Realizing that she would have to find a new way to relate to her condition brought new challenges. When telling her children and other family members, they all took it in stride.

But she had to adjust to dealing with doctors, various tests, and the fact that on many days, she didn't feel all that fabulous. She also found herself buying assistive devices that she thought she'd never have to use—a cane, manual wheelchair and shower chair.

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She credits her husband's love, enormous support and encouragement for helping her to be comfortable with disclosing her MS, and to be open about using a cane. In addition to the first red paisley cane, she now enjoys several with different designs.

She also credits her former employers at a funeral home with not treating her any differently because she has MS. "They never treated me with pity, and that's a wonderful thing," Pietrangelo says. Several situations brought about a lot of humor—like the time Pietrangelo was tired and sank down in her wheeled office chair. A co-worker decided to take her for a spin around the office.

Pietrangelo's husband Jim is also her caregiver, but that didn't stop her from wanting to resume household tasks herself, as well as other things. It's important for her to be independent. "What kind of wife would want her husband to stop doing dishes?" she mused. She also wanted to prepare dinner every night, which she still does. But at the same time, she realizes she needs some assistance.

Pietrangelo also relates the joys of life—the opportunities for travel in the U.S. and abroad, new experiences, and visits with family and friends. As she writes:

Just because I have MS, doesn't mean that all other life events stop. They don't. Whatever the state of my health, life goes on around us and, ready or not, we've got to participate.

She says, "All that has resulted in a major shift in my attitude, my way of looking at the world, and the way the world looks at me – or at least my perception of how the world looks at me. I'm a much more patient person, more content, and more confident than I've ever been, even as I've lost some of the independence I so prized."

Then she came face to face with another health scare. In late October 2010, just as she completed *No More Secs!*, Pietrangelo was diagnosed with triple-negative breast cancer—the most aggressive form. Again, she recounted her experiences on Care2.com. She, her husband and their families faced that challenge as they always have—head-on. Now that she has completed treatment, her prognosis is excellent, but she will need regular follow-up doctor visits for some time.

"When it comes to MS, it's a mystery, but doctors know how to deal with cancer," Pietrangelo reflects. "Look for doctors who can spend time with you. I had a one-hour chemo class where all of us could ask questions. One doctor, to my amazement, actually provided her home phone number, just in case we needed to contact her. The level of care was fabulous, and I never felt rushed by any doctor. They always took the time to answer questions thoroughly."

"Another thing that struck me was how happy many cancer patients are. You come to know how valuable life is through this experience, and how it's best to appreciate every moment that you have. I learned that from working at the funeral home, too. Death is sudden and unexpected, and it feels very unfair—especially when it happens to a young person. Really, today is all you have."

What's next? Now that her memoir is behind her, Pietrangelo is outlining a novel and is busy developing story lines, although she says she will probably focus on different themes from medical issues.

"I had always wanted to write, but I never thought of it as something I could do. It is wonderful now to do something that I love," Pietrangelo says. Her advice to other authors? "Write what you love, and be as stubborn as you can be," she says.

Throughout the book, readers will be encouraged by Pietrangelo's humor, optimism and positive approach to life. As she concludes in her book:

Don't ever be so grown up that the child inside you dies. Mine is alive and well, eager to see around the bend.

Visit www.nomoresecs.com to learn more about the book. Find Ann Pietrangelo on the Web at www.AnnPietrangelo.com and www.msmaze.com. ■

Carrie Smoot is a Northern Virginia freelance writer.





INCLUSIVE SCHOOLS WEEK

DEC 5 -9, 2011

The Inclusive Schools Network is pleased to announce the 11th Annual Inclusive Schools Week will be celebrated December 5–9, 2011, in classrooms, schools, and communities throughout the world. Inclusive Schools Week™ (ISW) highlights and celebrates the progress schools have made in providing a supportive and quality education to all students, including those who are marginalized due to disability, gender, ethnicity, geography and language. It also provides an important opportunity for educators, students, and families to discuss what else needs to be done to ensure that schools continue to improve their ability to successfully educate all children. ISW is sponsored by the Inclusive Schools Network at Stetson & Associates, Inc.

This year's theme ***"Awareness to Action: Moving Forward"*** continues the dialogue started during the 2010 celebration about how schools can make progress on their journey toward excellence by following a path of reflection, planning and action. This year's Celebration Kit contains updated resources to plan a successful Inclusive Schools Week™ celebration and includes new tools aimed at supporting schools in the process of becoming more inclusive.

The 2011 Celebration Kit will be available in Fall 2011 on Flash Drive or download by visiting the new website at www.inclusiveschools.org.

Inclusiveschools.org has a fresh new look and a wealth of new and innovative resources. It is the home of the Inclusive Schools Network and the place to find updated information about Inclusive Schools Week 2011 and to order new ISW products. Leading up to the ISW 2011 Celebration there will be weekly postings of ideas, events, and resources to support schools in planning their ISW activities.

For more information about the Inclusive Schools Network and Inclusive Schools Week, please visit www.inclusiveschools.org or email inclusiveschools@stetsonassociates.com. Be sure to sign up for Inclusive Schools Network News for regular updates as well as other news and information related to building schools and communities that are welcoming of all children and youth.

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Standing Up For Life Without Barriers

A Parent Perspective:

By Vicki Beatty

When we started our family in 1995, we had hopes and dreams for our children like all new parents. When our son, Davis, was born with a genetic anomaly, our hopes and dreams became a little more practical but we still have them. Unfortunately, most people didn't have the same expectations for Davis as we did.

Now, at age 16, Davis uses a wheelchair and a walker. He eats about 50 percent orally, has limited verbal communication and has cognitive delays. Eight years ago, after a five-year fight, Davis finally got full inclusion at school. Because I strongly believe that inclusion should begin with the student in a kindergarten class, we were able to have Davis start kindergarten at age seven. Like any other child starting kindergarten, we wanted him to go to his neighborhood school with his brother who was also entering kindergarten. Because Davis was not in a special education "program," he had every legal right to attend his neighborhood school. We were informed that our home school was not accessible to people with physical disabilities and Davis would have to be bused away from his neighborhood school. We have faced many challenges raising a special child but never the barriers of a school system who hadn't complied with a federal law from 1992. This I couldn't stand for. My son was being discriminated against for the sole reason that he uses a wheelchair.

So what were my options? I could sit back and take it or I could do something about it. I chose the latter. I contacted the principal, school administration and school board members in the hopes that this was simply an oversight and would be corrected immediately. This was a little naive. I quickly realized they really didn't view my son's plight as a problem since there was a good school he could attend away from his neighborhood. I truly believe they didn't think there was anything wrong with their disregard for federal legislation, the Americans with Disabilities Act. For a full year I tried my best to resolve this situation. I made public comment at the Richmond City Special Education Advisory Committee. I contacted my newly elected school board member who showed an



interest but didn't follow through. During this time, I met with parents, citizens, grandparents and other children who were unable to access 95 percent of Richmond schools because of physical disabilities. This included a Vietnam Vet who lost both his legs in the Vietnam saving other soldiers. He has two children in the school system and couldn't, without difficulty, even get in the front door of the school. This infuriated me. I knew there was no turning back. Someone needed to stand up and put a stop to this; why shouldn't it be me?

I knew that the voice of two is a much stronger voice than one. We began to hold meetings with anyone who was interested in fixing this accessibility problem. This included my family, parents with disabilities, citizens with disabilities other families with children with disabilities and much to my surprise, parents of typically developing children. We named our group "Citizens for Full Access in Richmond" otherwise known as C-FAIR. As a group, we all agreed we didn't trust the City or the School Administration to fix this problem in a timely manner. Over the years, many of us had made complaints to the school system but nothing was done. At this point we knew the only way Richmond Public Schools would comply with the law was if they were forced to by the courts. A friend, who is an attorney, sent out feelers to many law firms across the Mid-Atlantic to see if any would be interested to take this case pro-bono. The response was impressive. We chose a firm and the meetings began between C-FAIR, individuals personally harmed, and the attorneys. In June 2005, we filed the lawsuit against the Richmond School Board, the city of Richmond, the City Council and the Mayor of Richmond.

The school board settled with us in January 2006 and agreed to fix the accessibility issues of all the schools in a five-year plan. A federal judge ruled against the remaining defendants but they quickly appealed. To make a long story short, we were overturned in the appellate court. The good news is that we still have a binding settlement agreement with the school board to remediate

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all of our schools.

There were many things that got us this far and we would not be successful without each one. I am always the person looking for the shortcut, the easiest way to get somewhere. In this situation I don't think a short cut would have been successful. One of the biggest hurdles we had was public awareness about people with disabilities. This has been a cruel realization for me. If people are not directly affected, they don't notice or care. I knew we needed a little PR.

People needed to know how these barriers affected us all. I reached out to the media and was lucky enough to catch the interest of TV reporter from our local NBC station. She did multiple stories over about a six-month period. The newspapers didn't do much but they did print "letters to the editor." Richmond also has a large free newspaper circulation (Style Weekly, City Edition). Both did cover stories on the lack of accessibility. The use of the media cannot be downplayed. We needed the citizens of Richmond to be outraged that this was going on.

The last thing we did was to create a petition that "requested the City Council and the Mayor to fund the Richmond School Board enough money to allow them to make the schools accessible." Members of C-FAIR and friends helped to circulate the petition and we ended up with about 500 signatures. A self-advocate presented the petition to City Council prior to the budget hearings in hopes of including some money for the ADA compliance.

As parents of a child with disabilities, we find inequities to our children daily, but that doesn't make it OK. If we don't stand up and say "we're not going to take this anymore" it will continue and our children will continue to be discriminated against. If we don't stand up and say "No More" then Virginia will remain at the bottom of the list in funding the disability community. If parents don't stand up, then it remains a status quo to violate the civil rights of people with disabilities. I know I can't do that. If someone had stood up years ago, my son would have attended his home school with his brother and the neighborhood kids. My friend would have been able to watch his girls perform in the school play instead of waiting outside to hear them tell him about how good they were.

By September 2011, approximately 75 percent of all the remediation projects in the settlement agreement have been completed. Every Richmond public school is now

physically accessible. There are still some projects remaining such as some elevators and playgrounds but the progress has been impressive. We meet monthly with a mediating Federal Judge to make sure the settlement is on track. These meetings have been imperative to the timely remediation.

As a society, we agreed a long time ago that it isn't legal to discriminate against a person because of their race. Nineteen years ago we said it isn't legal to discriminate against a person because of their physical disabilities. I believe it is best to resolve illegalities without litigation but sometimes there is not an option. Filing a lawsuit was our last option. So what can parents do? Speak up for the child who can't do so for themselves. If your child is being discriminated against as a child, just imagine what will happen when they become an adult. If we change the course now, our children will have a better chance at a life without barriers. ■

Vicki Beatty is a 2002 Partners in Policymaking Graduate and is currently working as a "family/parent" voice on several projects at the Partnership for People with Disabilities.



Davis and a helper at the 7th grade field day at Alber Hill Middle School in Richmond City.