

THANKS TO OUR BOARD!

-Deanna Tharpe, Executive Director

It is amazing to me how much our little support group has grown in the past five years. As I look back at our first few activities, it seems worlds away from our monthly education program for children with disabilities or our annual educational conference that will be held in February. And never did I think that our little organization would host such great workshops, hold a beautiful gala each year, or win a National Parent Group Award from the National Down Syndrome Congress. But upon closer inspection, I don't know why I am surprised. We have a great group of people pushing to "educate, advocate and believe." They are our Board of Directors and they are not just "show up quarterly" board members. They are truly a "working board."

Each of them brings to the table an area of focus or expertise. Some are parents and some are teachers. Some are healthcare professionals and some are caring community members. They are all interested in advancing opportunities for persons with Down syndrome. They are all truly caring individuals who have given of their time (and sometimes money and always hard work) to help our organization be the best it can be. So, as we usher in new directors and say goodbye to former directors, let's give every one of them a big thank you.

Former directors who we would like to recognize are Nancy Holmes, Missy Merritt, and Marilyn Powers. Thanks so much for your input and your time. Your efforts were appreciated! We welcome our newest directors: Melynda Hutchings, Billy Trenado, and Vicki Trenado. Melynda is the Clinical Educator at Paris Regional Medical Center. Billy & Vicki Trenado are the parents of an adult son with Down syndrome.

And to our directors who are serving on our board today: Tiffany Phillips (Chairperson), Summer Allan (Past Chair), Gail Pitt (Vice-Chair), Donna Wilkerson (Secretary), Sabra Vaughan (Treasurer), Johnnie Stewart, D'Anna Graham, and Jennifer Cross. The next time you see one of our directors, acknowledge their great service with a sincere "thank you" and know that your organization is in good hands.

Survey for Siblings

Here is an opportunity to assist another Genetic Counseling student complete her Master's Thesis by taking a very brief survey. This survey is for women, age 18 and up, who have a brother or sister with Down syndrome. The anonymous survey will help this student (also a sibling) determine how having a sibling with Down syndrome affects a woman's reproductive choices. She also needs participants who do not have a sibling with Down syndrome. We hope you will pass along the link to this survey to others who may fit the subject criteria.

http://www.surveymonkey.com/s.aspx?sm=I0xV05HGqnL_2f17kPG_2feqmw_3d_3d

Insurance Bill Submitted to Texas House and Senate

Last session, the DS support organization *Down by the Border* worked with their state representative and senator to introduce a bill relating to a medical assistance buy-in program for children with certain developmental disabilities. However, it did not pass. On Nov. 11th, Representative Eddie Lucio III officially re-submitted a bill before the Texas House of Representatives concerning affordable insurance for Texas families with children with disabilities such as Down syndrome. Because of the early submission it will be able to be presented early in the legislative session.

House Bill 67 and Senate Bill 167 authorizes the development of a Medicaid buy-in program for children with developmental disabilities who are described by 42 U.S.C. Section 1396a(cc)(1) and whose family incomes do not exceed 300 percent of the applicable federal poverty level. This would include children born with Down syndrome. The monthly premiums will be set according to a sliding scale that is based on family income.

This issue is of great concern to many families with children with Down syndrome, as some are not eligible for Medicaid due to income and private insurance will not allow them to afford early therapies and medical care that would improve the later outcomes for their child. RRVDSS urges you to contact your local state representative or senator and ask him or her to fully support this bill. Remember that your voice and your actions will be on behalf of all disabled Texas children.

RRVDSS Annual Christmas Party

The Christmas party date has been set for Saturday, December 6, 2008 from 6 – 8 pm at the Down Syndrome Resource Center in the Village Shopping Center in Paris. As usual, the party will be a “bring a dish” event where attendees are asked to bring a favorite holiday snack, dessert or appetizer. RRVDSS will provide drinks. Again, this year, the party will include a visit from St. Nick who will be available for pictures. (RRVDSS will be taking pictures, but you are welcome to bring your camera to take your own.) We do ask that you bring a small gift (valued at no more than \$10) for any child attending with their name displayed prominently on it for Santa to give to them. You may bring the gift by the center beforehand if you wish. RSVP is requested but not required. To RSVP, please call (903) 783-1922.

Educator of the Year

Each year, the RRVDSS honors an educator that has worked to improve the lives of individuals with Down syndrome in our community. Any member of RRVDSS is encouraged to nominate a professional from the education community for this award. Nomination applications are available through RRVDSS either by mail or by download from the website. The deadline for acceptance of nominations is January 5, 2009. This is a great way to honor that special teacher, administrator or therapist that has increased opportunities for one child or many; that has made a difference in the education of persons with Down

syndrome, either currently or in the past. The award will be presented at the Snowflakes & Diamonds Gala to be held on Saturday, January 31, 2009.

Ignoring God's Children

- Clay Boatright

It is startling to see your life depicted on a television show, especially when that show is a top-rated crime drama. This week's episode of *Law & Order*, titled "Challenged," showcased the challenges facing millions of American families, including mine.

The plot revolved around Pete, a 47-year-old man with intellectual disabilities who had been sent to a state institution by his parents when he was only 3. Willowbrook, the real-life New York institution closed in 1987, was described as a "hell hole." Now living in a community home, Pete today enjoyed his unique group of friends, diverse caregivers and the respect of his employer.

This episode's moral dilemma questioned parents who willingly place a child with disabilities in a state institution. It bitterly, and quite accurately, described the immeasurable stress that disabilities bring to a family and the lack of support they receive.

The writers, however, made one mistake. Several times the dialogue referenced, "that's how things were done then," suggesting times have changed. For many families, things have hardly changed at all.

As the parents of 8-year-old identical twins with severe developmental disabilities, my wife and I have come face to face with this moral dilemma. Our pediatrician recently told us that we should "prepare to place them somewhere" in the next couple of years. In other words, he recommended we institutionalize our children.

This happened in 2008, not 1964. While many parents make this difficult decision, it does not come easy. As reported in *The Dallas Morning News*, all 11 Texas "state schools" for people with developmental disabilities are currently under investigation by the Department of Justice for alleged abuse.

Most families want to stay together. However, as shown on *Law & Order*, the physical, emotional and financial strain on a family without support can be insurmountable. Community-based services cost less than institutionalization, but Texas forces people with disabilities to endure waiting lists for nearly a decade before receiving help. Not surprisingly, for families who can no longer go it alone, there is no waiting required to place their child into our DOJ-investigated institutions.

With almost 100,000 people on waiting lists and more citizens institutionalized than in any other state, Texas ranks among the worst five states in the nation for disability services. Collin County has the lowest per capita funding for people with developmental disabilities in Texas. In cruel irony, Plano was recently named the wealthiest city in the United States.

In other words, the most prosperous city in America is at the bottom of the bottom for helping God's children most in need.

The lack of adequate care for people with disabilities is pervasive. Earlier this week, local news aired video from a Dallas County school bus showing a driver choking a student with disabilities. While most professional caregivers are compassionate, abuse is not isolated to certain areas, just as it was not isolated to the 1960s.

Caring for people is a matter of choice. Our state lawmakers can choose to end the waiting lists, while the federal government can choose to provide funds to upgrade education, housing and employment options. Our schools can choose to improve staff training and provide quality programs and supports. Our churches can choose to respond to God's word and "treat with special honor" those he created differently.

While these choices are not cheap, the costs pale in comparison to the destruction of families who have no choice at all.

This op-ed is reprinted with the permission of the author. Clay Boatright is president of The Arc of Dallas, and serves on the board of directors for The Arc of Texas. Clay and his family live in Plano.

DS Birth Rate Up in UK

A new study by the Down Syndrome Association in the UK has given Britain newspapers quite a lot to print about this week. Statistics show that after the widespread introduction in 1989 of pre-natal screening for Down syndrome, the number of babies born with the genetic condition fell from 717 a year to 594 at the beginning of 2000. But in 2006, births of babies with DS were up to 749. The Down Syndrome Association completed a survey of 1,000 parents to find out why they had decided to continue their pregnancy despite a positive test result. The findings were interesting...and very enlightening.

Twenty-five percent of the parents said that they already knew people with Down syndrome or other disabilities and that had influenced their decision to continue with the pregnancy. Thirty-five per cent said they felt that life and society had improved for people with Down syndrome, while almost half had not believed they would eventually have a child with Down syndrome, and so had continued with the pregnancy.

This study is important because it shows the importance of awareness campaigns and grass-roots movements by local support organizations like RRVDSS across the United States. The NDSC has put together a national awareness campaign called "We're More Alike than Different" which features young adults with Down syndrome. RRVDSS has contributed to the campaign and uses the resource whenever possible. The real awareness starts (and acceptance of persons with Down syndrome begins), though... in the daycare, the preschool, the church

pew, the soccer field, the homecoming court, and in the workplace. And it works because our members believe in it and practice it...daily.

December DS Q & A: Declining Function

Q: My son is 50 years old and seems to be slowing down. He can no longer do some of the things he used to do. Is he developing Alzheimer's dementia?

A: The problem of declining function in an older person with Down syndrome (DS) is one of the most common reasons for visits to the Denver Adult Down Syndrome Clinic (DADSC). Alzheimer's is a progressive neurologic disorder that results in memory loss, personality changes, global cognitive (thinking) dysfunction, and functional impairments. Many caregivers are aware that autopsy studies have shown that virtually all individuals with DS have microscopic changes in their brain tissue that look just like the brains of individuals with Alzheimer's. From these data, many have concluded that dementia occurs in virtually all individuals with DS. But some experts believe that symptomatic Alzheimer's dementia may be no more common in individuals with DS than in the typical population. But when it does occur, it manifests itself 15 to 20 years earlier than in typical individuals. So individuals with DS who are in their 50s and have a decline in function may have Alzheimer's. However, in typical individuals, and even more so in individuals with DS, many other medical, psychological and social issues can also cause these same symptoms. So part of what we do at the DADSC is explore whether other, treatable issues might be causing the decline in function.

One of the issues that must always be explored in a person with declining function is depression. Some individuals with DS have the verbal skills to express feelings of sadness and hopelessness. In others we have to look for other clues such as frequent crying, isolation, or loss of interest in previously enjoyable activities. Depression can be quite hard to distinguish from dementia, and, of course, they can coexist. Sometimes only a trial of an antidepressant medication can answer the question as to what component of the symptoms are attributable to depression.

Loss of sensory input due to poor vision and or hearing can cause a decline in function. Not infrequently these conditions can be challenging to treat because the individual with DS does not want to wear glasses or hearing aids or is not a good candidate for cataract surgery, for example. Still, medical providers and caregivers should look for these problems and attempt to correct them as much as possible.

Some other medical issues which should be explored are an underactive thyroid gland (hypothyroidism) and wheat sensitivity (celiac disease). These illnesses can be easily screened for with blood tests and are treatable.

Another common medical cause of decreased function is obstructive sleep apnea. This is a condition in which the tissues of the throat block the airway during sleep causing pauses in breathing which may or may not have been noted by caregivers. Many patients with sleep

apnea are noted to snore heavily (though not every one who snores has sleep apnea, and not everyone with sleep apnea snores). This abnormal breathing interferes with sleep enough that individuals may experience abnormal drowsiness and have an overall decline in function. The best way to test for sleep apnea is with a sleep study done in a sleep lab. Most major hospitals have sleep labs. In my experience, the sleep lab at National Jewish Hospital is especially good at working with individuals with intellectual disabilities. Sleep apnea is treatable, and the treatment can dramatically improve function.

Conditions which cause pain or discomfort may also lead to a decline in function, and we all know that individuals with DS frequently do not express pain symptoms the way typical individuals might. Occult dental disease, sinusitis, constipation, urinary tract infections or joint pain should be looked for and treated.

Abnormalities of the brain or spinal cord, while fairly uncommon, can also cause symptoms virtually indistinguishable from Alzheimer's disease. A condition of too much fluid around the brain — normal pressure hydrocephalus — can cause dementia, urinary incontinence and abnormalities of gait. Compression of the spinal cord due to instability in the neck bones (atlantoaxial instability) or to narrowing of the space for the spinal cord (cervical stenosis) are potentially treatable. At times the patient's symptoms and physical exam can be enough to "rule out" these conditions, but in some cases doctors might recommend further testing such as CT or MRI scans.

Myriad social issues can also cause changes or declines in function: the loss of a parent or caregiver, changes at work or at the day program, new living arrangements, etc. At the DADSC, our social worker Heather Luhrs and I question clients and caregivers extensively to explore what social changes might have led to alterations in behavior. Frequently, the social changes cannot be remedied, but we can usually give advice on how to help the individual with DS adapt to the changes.

All of us move a little more slowly as we age, but dramatic declines in function are not a normal part of aging. Individuals with DS who have sudden or dramatic declines in their abilities should have a thorough medical and psychological evaluation. Many declines are treatable and individuals with DS should be expected to be healthy and functional into old age.

For much of this information I am indebted to Dennis McGuire, Ph.D. and Brian Chicoine, M.D. and their book *Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges* published by Woodbine House Publishing.

The information contained in this column is for general information only. It is not intended as medical or psychosocial advice, and should not be relied upon as a substitute or consultations with qualified health professionals who are familiar with your individual medical or psychosocial needs. Full article reprinted with permission of the Denver Adult Down Syndrome Clinic.

Product Review: Buckle Boss

How do I keep my child with a cognitive disability in their seatbelt? Help is on the way! Having had this problem myself with my son with DS, I had resigned myself to the fact that I might not ever be able to do it without a few years of maturity on him.

We took advice from a friend and purchased a seatbelt alarm. That was great if you wanted to know when he took it off, but not much help keeping it on. In fact, he liked that it made an irritating beeping sound every time he did take it off. You can see where that is going, I am sure. On a long trip to the in-laws for a holiday last year, my husband rigged a jacket sleeve over the seatbelt latch. That worked for about 100 miles until Houdini figured that one out, too. It was a good idea, just wasn't Joel-proof.

And, of course, we tried the old-fashioned methods: rewards, positive reinforcement, stopping the car until he put it back on (that was a laugh), punishment, scare tactics (yeah, that one really worked, too), threats of bodily harm, and (and yes, I am ashamed to admit it) even the dreaded wooden spoon. But nothing worked. Oh, of course, some days he would wear it all the way to school and all the way home. But some days, it was a wrestling match in the back seat with brother until somebody screamed and somebody cried. This didn't do much for my Miss Clairol budget, and I was constantly in worry over whether he had silently un-clicked it without me knowing. It's your job to keep you child safe...and no seatbelt on meant I was not doing my job!

At wit's end last week, I ordered a new product called the Buckle Boss, made to keep those seatbelts locked. Well, we'll see about that when the Buckle Boss meets Joel the Boss. I eagerly unwrapped the package upon its arrival in my mailbox and was a little shocked to see this lightweight piece of plastic. How in the world would this keep my son in his seatbelt? Amazing! It fits over the part of the seatbelt with the release button and the tiny slots keep little fingers from pushing the release. To release it, you stick a small object like a Popsicle stick (or another seatbelt) through one of the slots to push the release button. The great thing is, it doesn't actually LOCK it, so getting out of it is pretty simple if you have the right tools. The secret is: don't keep the right tools in the back seat! And, it is totally portable. Just put it in your purse and take it wherever your child might need it.

After using it, I can safely say that it really does work. At least on my child, that is. If you want more information, go to www.buckleboss.com and check it out. The cost of one Buckle Boss is \$14.00. The other great thing: if your child is more of a Houdini than mine, they offer a money-back guarantee. So, for now, we are safe again in the car. And that, my friend, is priceless.