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Volume 2, Issue 2  
December 2008



MEDICALLY FRAGILE CASE MANAGEMENT PROGRAM

# Connected



## Happy Holidays

Welcome to our second Newsletter!

Our spotlight this month is the Davis Family. Sarah finds solace in journaling and poem writing about her life with her son who is on our program. Enclosed are two poems written by her. I think you may find her work insightful.

We are very pleased to announce that we now have had three Family Networking meetings. Our initial meeting families had the opportunity to get acquainted. The families were interested in having someone from all of the entities involved with Mi Via (the Self Directed Waiver Program) present at the next meeting. Medically Fragile, Consumer Direct Personal Care (the agency who oversees the Self Directed Waiver), Public Partnerships (PPL) who over sees the financial aspect of Mi Via, and the Brain Injury Association came to answer questions that were puzzling them. This was successfully accomplished. As of August 2008 we have 29 families enrolled in Mi Via from the Medically Fragile Waiver. Many families have appreciated having the option of having self directed services and having the flexibility for their children while others have experienced some frustrations with the development of a new program.

We will be highlighting information in our newsletters that may have helpful information about our program. Many times we get caught up with daily life activities and may not have given some thought to processes that are in place and how they work with all the entities

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University of New Mexico-Health Sciences Center-Center for Development and Disability

University Centers for Excellence  
on Developmental Disabilities

involved.

The MFCMP web site is up!! This is going to be a work in progress. But it's a beginning.

Go to: [www.cdd.unm.edu](http://www.cdd.unm.edu)

Click on Programs (on the left side of the screen)

Click on Case Management Initiatives Division

Click on Medically Fragile Case Management Program (top of the screen)

The picture on the web site is of Emma. She lives in Las Cruces and has osteogenesis imperfecta.

We will be changing pictures of children/individuals/families regularly. In order to do this we have to make sure that we have the appropriate release form signed. If you have any pictures that you would like to appear on our website for consideration or want to write an article to become our spotlight family, you can submit them to either your case manager or me,

Lynn Griffin at:

[legriffin@salud.unm.edu](mailto:legriffin@salud.unm.edu)

I am still collecting e-mail addresses to forward any updates between newsletter publications.



### Special points of interest:

- *Developmental Disabilities Info*
- *Geraldo Rivera News Spotlight*



## Medically Fragile Program TIPS: *A Friendly reminder*

When we receive services in our homes, many times we begin developing a closer relationship with the staff who are in our homes. Many of us may have retained a nurse or a home health aide for numerous years. Our schedules and lives rely on the staff, and we become dependent on them. We often ask staff to be flexible with us as our lives can be often unpredictable. We are often fortunate to find someone who is willing to accommodate us with some flexibility.

One thing we often forget though, is that the staff person in your home is employed by an agency. That person is accountable for their time to that agency. We need to take this into consideration when asking staff to alter their schedule to accommodate our needs. The agency providing service must be informed ahead of time of any changes in schedule. Contacting the agency is greatly appreciated to keep scheduling accurate and consistent. Please keep this in mind in the future.

The automobile maker, Henry Ford, once said:

*"Coming together is a beginning;  
keeping together is progress;  
working together is success."*

**Good news:** As we have all gone through diagnoses of our children, some people have expressed leaving with a sunken heart. Information offered was inaccurate and often did not reflect the joys and positive aspect of raising a child with a disability.

### **US Medical Professionals Must Provide Families Current Information on Genetic Disabilities**

On September 25 the Prenatally and Postnatally Diagnosed Conditions Awareness Act was approved by the US House and is on its way to President Bush for signature. This bill was made as an amendment to the Public Health Service Act with the intention to make medical professionals provide accurate, current information on Down syndrome and other genetic diagnosis when a parent has a prenatal or postnatal (up to 12 months) diagnosis for their baby. Currently the information given to parents is outdated and inaccurate according to current research and services that are available to families today. In addition, medical professionals must provide information for support services to these families, so they will know they are not alone in raising their child and will have the opportunity to speak with families also experiencing raising a child with the same disability.

## Family Spotlight: *The Davis Family*

### You are loved

I told my son he is loved  
We love him and want his best  
I look at him in amazement  
One moment I could snuggle him  
The next moment is for time out

You are loved sweet boy  
No matter how you act  
No matter a bad attitude  
We love you just as you are  
Though times we want to fix things  
You are perfectly our son  
You are loved.

By Sarah Davis

*A Mother*

### No Crisis Now

No crisis for now  
He's growing and eating  
He's laughing and talking  
Body is functioning well  
He's aware of surroundings  
No crisis for now

He's singing, loves music  
He's reasoning with us  
He has incredible memory  
He says great things

*No crisis for now*

By Sarah Davis

Behavior struggles?  
Yes

Tantrums uncontrolled?  
Yes

Speech delays?  
Yes

Physical impairments?  
Yes

**No crisis for now**



## “HOLIDAY BLUES”



The holidays are supposed to be a time of happiness, good cheer, joy, fellowship with loved ones and optimism for the coming New Year. But it's also a busy, stressful time. We have more things to do, more things to buy, more traffic to fight, parking lots and stores are crowded, other people are rushed and difficult. The extra demands on our time, attention, energy and finances can be very stressful. At the same time, we are bombarded with images of joyful, carefree people having fun with friends and family.

But sometimes everything is not “merry and bright.” All these stressors can trigger the “Holiday Blues.” Holiday Blues can range from mild sadness to severe depression. People can get “the Blues” when they are dealing with unresolved issues such as:

- ~ Past losses.
- ~ Unresolved grief.
- ~ Expectation of a significant loss.
- ~ Negative comparisons between past and current situations.
- ~ Disappointment.
- ~ Comparisons between images of holiday joy and the reality of one's current experience.
- ~ A sense of increased isolation and loneliness.

This sadness or depression can be prevented or minimized:

- ~ Establish realistic goals and expectations for the holiday season.
- ~ Don't look at the holiday season as a time to cure all problems. The holidays do not prevent sadness or loneliness.
- ~ Limit your drinking.
- ~ Accept your inner experience and don't force yourself to express certain feelings.
- ~ If you have recently experienced a loss, such as a death or romantic breakup, tell people about your needs.
- ~ Know your spending limit and stick to it. Enjoy free and low-cost holiday activities. Don't set yourself up for future problems by buying things you can't afford.
- ~ Express your feelings in a constructive, honest and open way.
- ~ If you need to confront a person with a problem, begin your sentences with “I feel;” avoid accusations.

### **Kids Get Depressed Too**

While many of us may think of depression as an adult disorder, kids can experience depression too. Symptoms of depression in kids are similar to those in adults. A child who is depressed may:

- ✦ Complain of headaches, stomachaches, muscle aches or tiredness.
- ✦ Perform poorly in school, be frequently absent from school, or resist going to school.
- ✦ Talk about running away from home.
- ✦ Cry for no apparent reason.
- ✦ Be extremely sensitive to rejection or failure.

Children who are depressed can be helped. Just like with adults, supportive listening can help. And sometimes, a child or an adult may need medication and/or therapy.

**Provided by: JEMEZ HEALTH & HUMAN SERVICES INJURY PREVENTION PROGRAM**

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## FYI's: Developmental Disabilities Act

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In the important work that you do every day with people with disabilities -for which we again thank you - I'm sure you'll agree that there is no substitute for going back to source information for inspiration, guidance and confirmation.

I'm pleased to announce that the entire Developmental Disabilities Assistance and Bill of Rights Act (DD Act) - a comprehensive collection of legislation, hearings, manuals, reports and reviews - is now available at:

<[http://www.mncdd.org/dd\\_act/dd-act.html](http://www.mncdd.org/dd_act/dd-act.html)>  
[www.mncdd.org/dd\\_act/dd-act.html](http://www.mncdd.org/dd_act/dd-act.html).

The Developmental Disabilities Act has made a crucial difference in the lives and futures of individuals with developmental disabilities and their families. Through this legislation, federal funds support the development and operation of Councils on Developmental Disabilities, Protection and Advocacy Systems, University Centers of Excellence (formerly known as University Affiliated Programs), and Projects of National Significance.

In this <[http://www.mncdd.org/dd\\_act/dd-act.html](http://www.mncdd.org/dd_act/dd-act.html)> free online repository, you will see how the DD Act

has provided structure in support of all people with disabilities, and has evolved to assist people with developmental disabilities to pursue meaningful and productive lives:

- the early legislation, emphasizing advancement of scientific understanding, professional education, and ensuring access to, and safety of, institutional facilities;
- changes over time, which focused on the efforts of families, professionals, and state agencies to improve supports for all people with developmental disabilities;
- current emphasis on fundamental systems change, including legal services, advocacy, and capacity building at the state and local levels.

For their gracious help in assembling this collection we deeply appreciate the contributions of the Connecticut and Texas Developmental Disabilities Councils. Their respective archives of historical documents have helped to make this history of the Developmental Disabilities Assistance and Bill of Rights Act as complete as possible.

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## Helpful Information

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Parent your special child with  
**Love and Logic**®

As the co-creator of [Love and Logic](#), child psychiatrist Foster Cline MD has adapted Love and Logic's powerful- yet simple- parenting tools to the special challenges of raising special needs children. He has teamed up with Lisa C. Greene the mother of two children with cystic fibrosis to bring you new [special needs resources](#) which include an award- winning book, audio, video, live and web-based support.

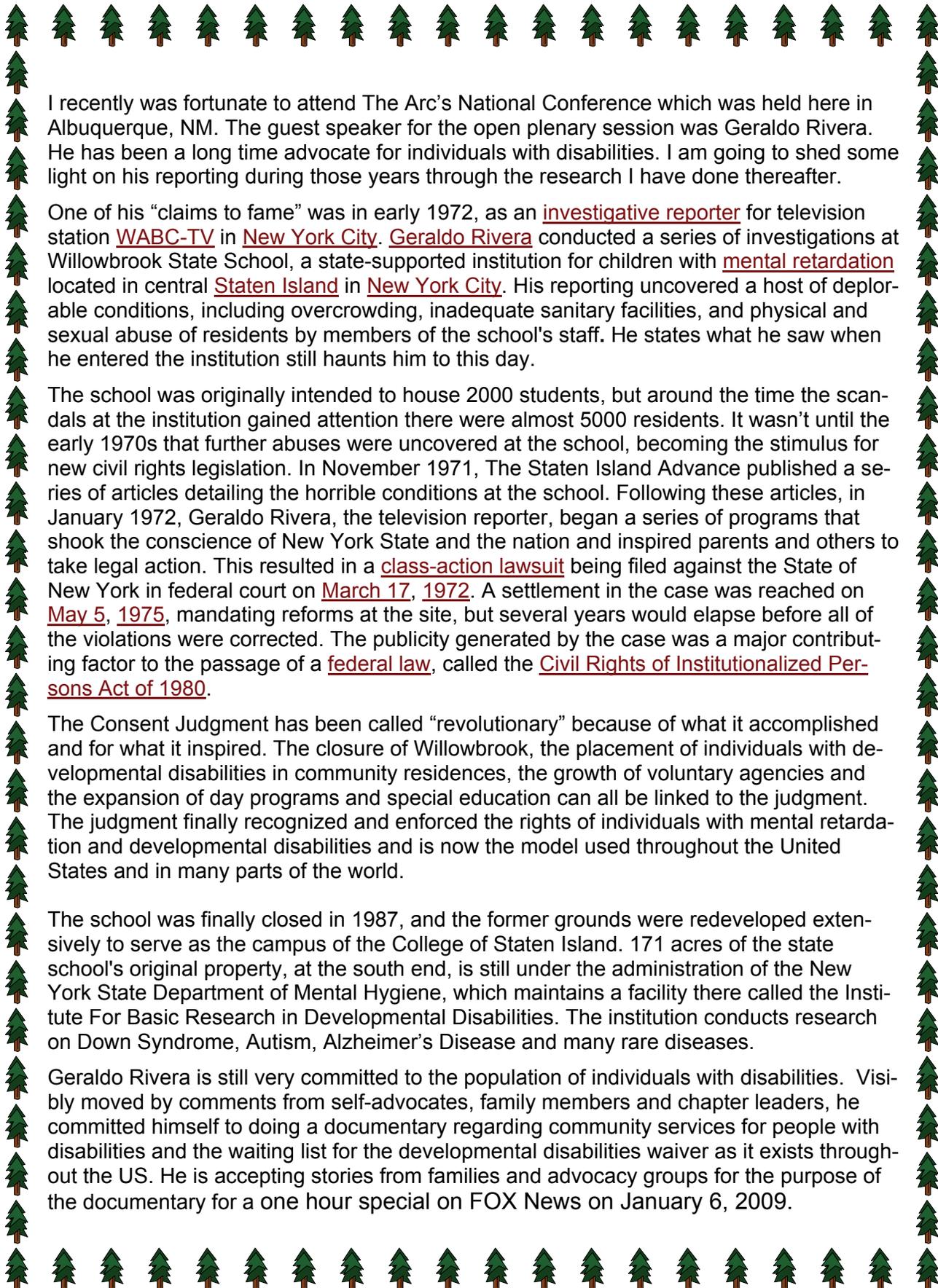
Book available at [Love and Logic](#), [Amazon](#), [Barnes & Noble](#) and your local bookstores.

[www.barnesandnoble.com](http://www.barnesandnoble.com)

**Special parenting skills are needed to raise kids with special needs.**

Whether your child has allergies, asthma, diabetes, cancer, cystic fibrosis, dietary limitations, weight problems or any other health issue, you'll discover how to:

- **Promote responsibility** without nagging, lecturing or yelling
- Effectively **respond to difficult questions** about medical issues
- Handle **refusal to take medication** or do medical treatments
- **Avoid power struggles** and other common parenting traps
- Facilitate your child's **transition to independence**
- **Empower your child** to make wise self-care decisions
- **Reduce frustration**, worry and fear
- Coach your child to **handle interactions with peers**
- Navigate sibling, family and couple **relationship issues**
- Encourage your child to **love life** despite health challenges



I recently was fortunate to attend The Arc's National Conference which was held here in Albuquerque, NM. The guest speaker for the open plenary session was Geraldo Rivera. He has been a long time advocate for individuals with disabilities. I am going to shed some light on his reporting during those years through the research I have done thereafter.

One of his "claims to fame" was in early 1972, as an [investigative reporter](#) for television station [WABC-TV](#) in [New York City](#). [Geraldo Rivera](#) conducted a series of investigations at Willowbrook State School, a state-supported institution for children with [mental retardation](#) located in central [Staten Island](#) in [New York City](#). His reporting uncovered a host of deplorable conditions, including overcrowding, inadequate sanitary facilities, and physical and sexual abuse of residents by members of the school's staff. He states what he saw when he entered the institution still haunts him to this day.

The school was originally intended to house 2000 students, but around the time the scandals at the institution gained attention there were almost 5000 residents. It wasn't until the early 1970s that further abuses were uncovered at the school, becoming the stimulus for new civil rights legislation. In November 1971, The Staten Island Advance published a series of articles detailing the horrible conditions at the school. Following these articles, in January 1972, Geraldo Rivera, the television reporter, began a series of programs that shook the conscience of New York State and the nation and inspired parents and others to take legal action. This resulted in a [class-action lawsuit](#) being filed against the State of New York in federal court on [March 17, 1972](#). A settlement in the case was reached on [May 5, 1975](#), mandating reforms at the site, but several years would elapse before all of the violations were corrected. The publicity generated by the case was a major contributing factor to the passage of a [federal law](#), called the [Civil Rights of Institutionalized Persons Act of 1980](#).

The Consent Judgment has been called "revolutionary" because of what it accomplished and for what it inspired. The closure of Willowbrook, the placement of individuals with developmental disabilities in community residences, the growth of voluntary agencies and the expansion of day programs and special education can all be linked to the judgment. The judgment finally recognized and enforced the rights of individuals with mental retardation and developmental disabilities and is now the model used throughout the United States and in many parts of the world.

The school was finally closed in 1987, and the former grounds were redeveloped extensively to serve as the campus of the College of Staten Island. 171 acres of the state school's original property, at the south end, is still under the administration of the New York State Department of Mental Hygiene, which maintains a facility there called the Institute For Basic Research in Developmental Disabilities. The institution conducts research on Down Syndrome, Autism, Alzheimer's Disease and many rare diseases.

Geraldo Rivera is still very committed to the population of individuals with disabilities. Visibly moved by comments from self-advocates, family members and chapter leaders, he committed himself to doing a documentary regarding community services for people with disabilities and the waiting list for the developmental disabilities waiver as it exists throughout the US. He is accepting stories from families and advocacy groups for the purpose of the documentary for a one hour special on FOX News on January 6, 2009.

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<http://cdd.unm.edu>



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**Useful Websites:**

- Parenting Children with Special Health Issues  
<http://www.parentingchildrenwithhealthissues.com/index.html>
- Information about HIPAA can be found HHS Office of Civil Rights  
<http://www.hhs.gov/ocr/hippa/>
- Family Center on Technology and Disability  
[www.fctd.info](http://www.fctd.info)
- AblePlay™ toy evaluations are the key to unlocking the magic of play for children with special needs!  
<http://www.ableplay.org/>
- Assistive Technology ReUse Program  
New Mexico Reutilization and Acquisition Model (NMRAM) is a onestop clearinghouse acquiring, repairing and distributing used assistive technology and adaptive equipment.  
[www.backinuse.com](http://www.backinuse.com)

