

Medically Fragile News

Winter 2011
Edition V

HAPPY NEW YEAR



Hope you all had a wonderful holiday season !

There have been many exciting things happening this year. As many of you may be aware our Family Advisory Board (FAB) presented at the Southwest Disability Conference. They did a fabulous job! It was very well received by parents and professionals. Our intention is to break up the presentation into segments for our brown bag Family Networking Meetings. The following series is on *Medical Home, Nursing, Nursing at School, and Hospice*. Please look for further notification.

What is a Medical Home?

A medical home is not a building, a house or a hospital. It is an approach to health care that emphasizes the partnership between pediatric clinicians and family. *PA Medical Home Initiative—Pediatrics, Policy Statement 2002*.

It is an approach to delivering primary health care through a ‘team partnership’ that ensures health care services are provided in a high quality and comprehensive manner. The core elements of a Medical Home “assures health and well being of children and their families through respectful family professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to the table. *Bishop, Wall, Arango, 2002-2004.*”

Most of all, a “Medical Home” is a name for health care that is family centered, compassionate and well coordinated.

What are the benefits of a Medical Home?

- * Promotes Health through Prevention
- * Healthier Children and Families
- * Reduces Health Care Costs

Information on state organizations that play a role in implementing various aspects of medical home, and includes links to their Web sites and contact information for the state of New Mexico please visit:

http://www.medicalhomeinfo.org/state_pages/new_mexico.aspx

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

University Centers for Excellence on Developmental Disabilities



Connected

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If you are interested in the development of Medical Home projects here are various links with information on the development of it.

<http://www.medicalhomeimprovement.org/projects/national.html>

NATIONAL HOME OF IMPLEMENTATION: **Website:** www.medicalhomeinfo.org



Annual Family Picnic: June 2010

We had a wonderful time at our annual Family Picnic at **Manzano Mesa Multigenerational Center** again this past year!

We had a great turn out and look forward to seeing new faces next year. We will be trying to book a Saturday event in hopes of expanding our group making it more accessible for those of you who are out of town to attend. Our hope is to expand our

gatherings to a semi annual event. We may consider another location for a winter, spring or fall event. Any suggestions would be appreciated. Please join us in the future for a day of fun! Here is a link to access other photos from the day.



<http://crickdesign.com/medfrag/>

If you have any suggestions and would like to help in planning please contact me at:

legriffin@salud.unm.edu

Phone: 505-272-8801

Updates on MF Waiver

As many of you may be aware of the changes occurring at the state level for individuals on the Developmentally Disabled Waiver. Just to ease everyone's minds, there have not been any changes made to the Medically Fragile Waiver. The medically fragile population served through the program has proven to be a cost effective program with great benefits to them. If we hear of any news during the Legislative session, that starts on January 19, 2011, we will keep you posted. In the past families have participated at the Legislative session by talking with their senators and representatives about their child and the Medically Fragile Program. It's always a good idea that your legislators are informed about the importance of programs that help your child who is medically fragile.

Different types of respite care was mentioned in the last newsletter. The program is still working towards offering the services through Arca's Foster Care Program, where the child would be brought to a foster home where staff has been trained in providing appropriate care for the individual. Casa Angelica is also an option but is available to families only when a bed becomes available at the facility.

There are currently 56 participants being served on *Mi Via* through the *Medically Fragile allocation*. Participants see the benefits of the program, although there are many challenges that come with it. There are many changes underway from the state. From a participant perspective, it has not allowed services to continue as the program was initially intended.

For more information go to the state website as revisions occur. <http://www.mivianm.org/>

FAMILY SPOTLIGHT: *THE SACHSE FAMILY*



Hi, My name is Vonnie Sachse. Elliott and I have been married almost 18 years and are proud parents of four wonderful children. We have two boys and two girls. Our children are Evan, 13; Jeremy, 7; Hannah, 7; and Heather, 4. Hannah and Heather have Down Syndrome and Hannah receives Medically Fragile Waiver Services.

By trade, I am a social worker and Elliott is a 4-H Agent with NMSU Cooperative Extension Services. I no longer work due to the needs of my children but am proud to say that I worked at ARCA for almost 15 years in the Family Based Services Division and have worked in the field of Developmental Disabilities for 17 years.

Children are very precious to Elliott and me and we had hoped to have a middle sized to large sized family. We were very blessed and happy with each pregnancy. When our oldest was 5 years old we learned we would be having another baby. WOW! At 15 weeks we found out that our sweet little Hannah had Down Syndrome. A shock of course! There were many complications and Hannah was born at 26 weeks gestation by emergency c-section. That was the hardest time of our lives. Hannah was ,and still is ,a fighter. We were fortunate to have such a good medical team that believed in life and believed that Hannah was worth every effort they made to make sure that she would live and continue to touch our lives and the lives of others. Hannah stayed in the NICU for 92 days. When Hannah was a year old, our then 7 year old said, "Mom, we need to adopt a baby with Down Syndrome."..Tired and financially strapped from medical co-pays I, of course, said, "WHY?"...his innocent little voice responded, "So she doesn't think she's the only one." Well, we followed our young son's advice and we adopted. Our first adoption was a very sweet little boy who did not have Down Syndrome, but was a 26 week premie and had some medical challenges. Coincidentally, he was at the NICU the same time as Hannah. Jeremy is a charmer and a lover. He is so resilient and kind and compassionate. He has made great strides and his future is very promising. We only had Jeremy a little less than a year when we were introduced to our youngest daughter, a sweet little baby girl with Down Syndrome. We never thought we'd get to adopt a little girl with Down Syndrome or that we would have such a wonderful opportunity to adopt again, but as fate would have it we were meant for each other. When we met her birth parents Elliott thanked them for making our family 'complete'.

I think of the day our oldest son said we should adopt and I am so very thankful for his innocent, optimistic and compassionate look on life. Our family is complete thanks to the voice and thoughts of a 7 year old.

You never know where life is going to lead you. I never imagined we'd adopt a child(ren), much less children with special needs. At one point our house looked like a little DME supplier with oxygen tanks, cpt vests, g-tube poles, the works. You need hypafix tape, I got it. You need tubing, I got it. You need to know some tricks to oxygen and feeding tubes,..I got it. Through it all, I have to say we are truly lucky, blessed and happy. Our children have taught us so much more than we could ever teach them. I could go on and on about how wonderful each one is in their own way. Evan is smart, stylish and cool yet still manages to be kind; Jeremy is kind, funny and loving; Hannah is non verbal but her eyes talk and sparkle; Heather is a tornado with a fun fun fun personality. They have touched us, our hearts..and thrown up on the carpets quite a bit. HA!

Being a part of the DD community and getting to know other parents, providers and people who dedicate themselves to helping individuals with developmental disabilities and helping their families is quite the journey. I feel so fortunate to call many of you my friends, my confidants and mentors. I enjoy participating on the Medically Fragile FAB, LEND and any other group where I can learn, share and support. Our children with special needs require us all to participate in the *Village Parenting* philosophy ...but together we are all winners and we are all strong.

Things to Celebrate in the Disability World

Celebrating IDEA 35 years: Celebrating Access, Accountability, Achievement

During these last 35 years, *IDEA* also has developed a national infrastructure of supports that are improving results for millions of children with disabilities, as well as their nondisabled friends and classmates. Notably, many of the educational approaches, techniques, and practices employed by our nation's best teachers are the direct result of *IDEA* investments in rigorous education research, training, and technical assistance. Teachers can employ these approaches, techniques, and practices with confidence that they are likely to be effective.

Special education features instruction and interventions designed to meet the individual needs of each child with a disability.

Conditions Before and After *IDEA* (P.L. 94-142)

The current promising future of children with disabilities and their families stands in sharp contrast to conditions before *IDEA*. These last 35 years have witnessed significant changes as the nation has moved from paying little attention to the special needs of individuals with disabilities to merely accommodating these individuals' basic needs and then eventually to providing programs and services for all children with disabilities and their families.

What Makes Special Education Special?

Special education features instruction and interventions designed to meet the individual needs of each child with a disability. Through special education, the **United States** has developed instructional curricula and programs for teaching core competencies to children with disabilities. *IDEA* has invested in a research to practice model that has helped the country support improvements in special and general education. This infrastructure, in turn, has contributed to improved results for children with disabilities and their families over the last quarter of the 20th century and through the first decade of the 21st century.

Significant progress has been made toward protecting the rights of, meeting the individual needs of, and improving educational results for infants, toddlers, children, and youths with disabilities.

For more information on this article see at::

<http://www2.ed.gov/about/offices/list/osers/idea35/history/index.html>

U.S. Department of Education, Office of Special Education and Rehabilitative Services, *Thirty-five Years of Progress in Educating Children With Disabilities Through IDEA*, Washington, D.C., 2010.

Including Health Care Issues into IEP Process:

A Resource: <http://www.waisman.wisc.edu/wrc/pub.html>

Rosa's Law

A journey that began as one Maryland family's battle for respect and acceptance for their daughter and sister, Rosa, became a significant milestone in the ongoing battle for dignity, inclusion and respect of all people with intellectual disabilities when United States President Barack Obama signed bill S.2781 into federal law on October 5, 2010.

"Rosa's Law," removes the terms "mental retardation" and "mentally retarded" from federal health, education and labor policy and replaces them with people first language "individual with an intellectual disability" and "intellectual disability."

Networking Update

The Google MF Family Social Networking site was developed after our initial take off of our Wiggio Site. As we began this project, we saw the limitations of the WIGGIO site. Therefore the GOOGLE site was developed, called the **Medically Fragile Networking Site**, with FORUMS for families to share specific information with regard to interest and need. Many of you may have already received an invitation who I had email addresses for.

For those of you who have not joined yet I suggest you forward me your email address, or give it to your Case Manager. She can forward it to me and I can send you an invitation. This site has been designed with the input from the Family Advisory Board (FAB) for all of the families who expressed an interest who are on the Medically Fragile Program. As you view the site you will find more information regarding the FAB and the committee members. Many thanks to our LEND student this past year, Tiffany Miner, for all of her hard work in developing this site. Tiffany has obtained her Master's in Social Work and still remains active with the program. She has identified herself with her bio also "on the website." Our hope is that you find this site useful in making the connections with other families in similar situations. Suggestions are always welcome! If you are experiencing any difficulties, please contact me at legriffin@salud.unm.edu. I would be happy to assist you in any way I can.

The link for it is: <https://sites.google.com/site/mffamnetwork>, but first you need to receive an invitation to participate. This is a "closed group." This closed group that has been developed is meant only for families who are receiving services through the Medically Fragile Case Management Program through invitation only. Once you have received an invitation, you can accept the invitation to join. Take a deep breath and dive in. For those who are technologically challenged, this has been an education for me also. It's a whole new world out there. The emphasis is now on social media to share pictures, videos and stories. We have the ability to schedule and receive event notices, develop online communities to build relationships through the internet. Again, I emphasize this is a closed group that is only shared with medically fragile families who are choosing to participate from our program.

So What is Social Media?

According to Wikipedia, "*Social media*" is media designed to be disseminated through social interaction, created using highly accessible and scalable publishing techniques. Social media supports the human need for social interaction, using Internet- and web-based technologies to transform broadcast media monologues (one to many) into social media dialogues (many to many). It supports the democratization of knowledge and information, transforming people from content consumers into content producers."

Another Recycling Program Resource: CReATE

To view CReATE's updated refurbished inventory, visit <http://www.uatpat.org/create/>, click on "View the CReATE Inventory." If you do not see a device on the inventory that will fit your needs, contact CReATE. There are many more devices that have not been refurbished yet.

To acquire a device, follow the steps below:

1. Contact CReATE staff at 801-887-9398.
2. The CReATE office coordinator will take down necessary information.
3. The interested person will be contacted to set up an appointment for an evaluation.
4. After the evaluation the CReATE inventory will be reviewed to determine if there is an appropriate device.

To donate a device:

1. Contact CReATE staff at 801-887-9398.
2. The CReATE office coordinator will discuss the procedure for making a donation.

Faye Hauser
CReATE Office Coordinator
faye.hauser@usu.edu
801-887-9398

Permissions from Gordon Richins, CReATE

[link to story:](http://www.abqjournal.com/news/metro/0723546metro01-07-11.htm) <http://www.abqjournal.com/news/metro/0723546metro01-07-11.htm>



A parent on program, Lori Steward, thought this article would be of interest.

Friday, January 07, 2011

Shot Can Protect From Whooping Cough

[By Olivier Uyttebrouck](#)

Journal Staff Writer

Getting a booster shot for pertussis, or whooping cough, can save the life of a child — possibly your own, state health officials warn.

A growing number of pertussis cases in New Mexico threatens the lives of infants who are most vulnerable to the bacterial illness, the New Mexico Department of Health said this week.

"Infants are most susceptible to pertussis," said Dr. Maggi Gallaher, medical director for the agency's public health division. The bacterial illness can be deadly to infants, who can't be fully immunized before 15 to 18 months when they have received a complete series of vaccines.

The danger to infants is growing because of an increase in the number of cases, Gallaher said. The state logged 141 cases in 2010, up from 94 cases in 2009 and 85 in 2008, the Department of Health reports.

About 75 percent of infants who get pertussis are infected by a family member. More than half of infants infected require hospitalization and some die.

The Department of Health urges anyone ages 11 to 64 to get a pertussis booster shot included in the so-called Tdap vaccine, which also guards against tetanus and diphtheria. "The best thing parents can do to protect their children from diseases is to make sure all their immunizations are up to date," she said.

Pertussis protection

The pertussis booster shot is included in a three-part Tdap vaccine, which protects against tetanus, diphtheria and pertussis. Most commercial insurance plans cover the vaccine. The retail cost is about \$39.

Vaccinations are free for all children 18 and younger under the Vaccines for Children program. Uninsured kids can get free vaccinations at local public health offices. For locations, visit www.nmhealth.org and click "public health offices" under Find it Fast.

The Department of Health also offers guidelines intended to contain the spread of pertussis. They are:

Vaccination: Children under 7 should get a complete vaccine series. Anyone ages 11 to 64 should receive a Tdap booster shot.

Diagnosis: Anyone with a cough lasting two weeks or longer or unexplained coughing spasms should be evaluated for pertussis.

Treatment: Antibiotics should be used to treat anyone diagnosed with pertussis and their household members.

Caution - Stay home and avoid contact with people outside your household for five days after starting antibiotic treatment.