

Medically Fragile News

Centennial Care What it means to your family

Spring 2013
8th Edition



Special points of interest:

- Annual Family Picnic – Flyer Enclosed
- Centennial Care—Selecting an MCO
- Technology Update
- Join us on Facebook

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Centennial Care is the new name of New Mexico's Medicaid program, formerly known as Salud to most of you. Its design creates a single, comprehensive delivery system through four managed care plans, allowing for greater administrative simplicity. It emphasizes care coordination so that recipients will receive the right care, in the right place, at the right time, leading to better health outcomes.

Human Service Departments (HSD) is preparing for the implementation of Centennial Care that will go into effect on January 1, 2014. The first thing to look for that will directly effect you or your child is possibly having a different Medicaid provider. Several will remain the same but no longer be known as Medicaid Salud Programs. They now will be Managed Care Organizations (MCO's). The state has selected 4 (MCO's) to manage Medicaid. They are as follows:

- ◆ Blue Cross Blue Shield New Mexico
- ◆ Molina Health Care of New Mexico, Inc.
- ◆ Presbyterian Health Plan, Inc.
- ◆ United Health Care Community Plan of New Mexico

Key aspects of the Centennial Care waiver include:

- ◆ Greater administrative simplicity and reorganization of HSDs Medicaid Division to manage Medicaid more efficiently;
- ◆ Requiring care coordination for recipients to ensure they receive the right care in the right setting at the right time;
- ◆ Incentives to reduce the inappropriate usage of emergency rooms, including copays for nonemergency use of the emergency room;
- ◆ Strategies for encouraging healthy behaviors and use of the primary care system in order to prevent health problems and to reduce chronic disease; and
- ◆ Efforts to expand the ability of health care specialists to reach rural areas through the use of technology, such as Project ECHO (Extension for Community Healthcare Outcomes).

A letter will be sent to your home in the fall of 2013. If you choose not to change from the provider you are currently using, you do **nothing**. If your provider is not listed, you will have to **select** one of the current providers listed. If you fail to do so, you will be **assigned** a new provider.

The Agreement in Principle letter can be found on HSDs website by navigating to: <http://www.hsd.state.nm.us/> and then clicking on "New Mexico Centennial Care" on the right hand side of the page. <http://www.hsd.state>.

Medicaid Recipient Web Portal—New Features

As of April 15th, Medicaid Recipients will be able to access the following NEW Features online:

- ◆ Request Medicaid Replacement Cards
- ◆ Select and/or change Managed Care Organizations (MCO)

University Centers for Excellence on Developmental Disabilities Education,
Research, and Services

WE'RE ON THE WEB! VISIT US ON FACEBOOK

<https://www.facebook.com/CDD.MFCMP>

It has arrived! We are now on Facebook! We have made a few other attempts for families to make web based connections over time. This time it looks as though it is here to stay! UNM and the Center for Development and Disability have branded their Facebook pages, which now makes it official!

This is a wonderful opportunity for families to connect with one another who have similar life experiences. Please join us in this wonderful new online experience! Updates for the program will be posted on a regular basis.

CDD News—Encrypted Email

For all of you to be assured that your confidential information that is being transferred through email is secure, the email you receive from your Case Manager (CM) will require you to open it with a password. It will be a one time on-ly process to access the information. Your password will be needed thereafter. Bellow is a link to a youtube video, developed by our CM, Maggie Nechvatal, on how to go about getting established. It may take a few minutes to down-load, please be patient. This is in accordance of HIPAA compliancy. Thank you Maggie!

<http://www.screencast.com/t/GbLbxOIRLB>

Reminders:

Annual Survey

Annual Picnic

This serves as a reminder to please complete the annual family survey. It is important that we hear from all of you! Your input is valued. This helps us better understand the needs of your family. Please help us help you. The link to the online family survey is:

<http://www.surveymonkey.com/s/MFFAMILYSURVEY2013>

For the adults <http://www.surveymonkey.com/s/MFINDIVIDUALSURVEY2013>

**** Please see the enclosed flyer for the annual picnic****

Date: **June 23 at 2:00—4:00 PM**

Place: Manzano Mesa Multigeneraltional Center Sprayground

FMLA—Family Medical Leave Act

New Interpretation of FMLA Issued by the U.S. Department of Labor's Wage and Hour Division.

Recently, the U.S. Department of Labor's (DOL) Wage and Hour Division issued a new Administrator Interpretation that expands the Family and Medical Leave Act's (FMLA) current language to include adult children who are unable to care for themselves because of a mental or physical disability and whose disabilities occurred before or after the age of 18. The previous interpretation of the law was unclear as it applied to adult children with disabilities.

This Interpretation also clarifies FMLA-protected leave for a parent is not dependent on the age of the adult child and the onset of their disability, and broadens the definition of "disability" to reflect the Americans with Disabilities Act Amendments Act (ADAAA). Ultimately, this interpretation means that more parents will be able to take FMLA- protected leave from their jobs to care for their adult children with disabilities. Learn more about the FMLA and this new Administrator Interpretation from United Cerebral Palsy's (UCP) Website.

Reference Points from Pacer

Dual Eligibility for Those Who Qualify for Both Medicare and Medicaid

Medically Fragile Waiver and the Developmental Disability Waiver consumers in most cases do not have co-pays due to their Medicaid status, including pharmacy co-pays. A change *can* occur when the consumer is signed up for Medicare Part A, B, and D due to change in status of the parents Social Security payment. If the parent is collecting Social Security or Social Security Disability, it could possibly alter the payment amount of the individual receiving SSI. If the dollar amount goes too high the individual will no longer be eligible for SSI and would be then be receiving SSDI. They would also no longer be eligible for Medicaid but for Medicare. Individuals who qualify could then be enrolled in both Medicare and Medicaid, known as “dual eligible beneficiaries” or sometimes simply “duals.” Nearly 40 years ago, Congress expanded Medicare eligibility to non-elderly individuals with disabilities. Legislators simultaneously expanded the scope of Medicaid’s community-based long-term care benefits to make Medicaid our nation’s preeminent disability and long term care insurer. The goal then, as now, was to promote appropriate medical care as an alternative to hospital care and independent living as an alternative to institutional care.

There are programs available that can help with the costs of Medicare, for those who become “duals” such as QMB, (Qualified Medicare Beneficiary), Medicare category 040 or SLIMB (Specified Low Income Medicare Beneficiaries), Medicaid category 045. Programs may be based on income. For more information go to:

<http://www.newmexicosresources.org>

Look under Healthcare Programs: Medicare and Medicaid

WHAT IS QMB COVERAGE?

QMB (*Qualified Medicare Beneficiary*) is a special type of *Medicaid* coverage. It pays for all your Medicare premiums and cost sharing (*but not for any added services*). The *Qualified Medicare Beneficiaries (QMB) program* entitles individuals to payment of Medicare premiums as well as the deductible and co-insurance amounts on Medicare-covered services. To be eligible, the applicant must already have or be conditionally eligible for Medicare Part A (Hospital Insurance). Applicants/recipients eligible for Medicaid coverage under any other category may be eligible for coverage under QMB. QMB eligibility affords two advantages when an applicant/recipient is already eligible for Medicaid:

A. *Medicare premium part A is payable by Medicaid; and*

B. *Medicaid receives federal matching funds for purchase of Medicare part B.*

WHAT YOU MAY NEED TO DO IF ELIGIBILITY CHANGES:

The New Mexico State Resource Center will be able to help determine changes needed in the electronic system and what changes the consumer will need to do if any. This is done with a phone call and does not require traveling to an office. Please allow enough time, possibly 30 minutes with The Resource Center to make the necessary changes. Before you call the Resource Center here are a few things the consumer, the parent, the guardian or the consumer’s Case Manager will need. Please have the following information available:

- ⇒ Medicare Number
- ⇒ Medicaid Number
- ⇒ Social Security Number

You can contact the NM Resource Center at [1-800-432-2080](tel:1-800-432-2080) Option # 1.

Office hours are 8 am to 5pm, Monday through Friday

* If further assistance is needed contact: Suzanne.Shaffer@state.nm.us

WHAT NOT TO DO:

- ⇒ Contact pharmacies requesting a change. They are unable to make the changes in the system.
- ⇒ Contacting NM Resource Center without the legal guardian available to make a decision if changes in the consumer’s requested benefits are needed. Sometimes consumers have signed up for Medicare benefits that the State does not cover, this means the consumer is not eligible for no co-pay on pharmaceuticals, etc.
- ⇒ Delay in contacting *Suzanne Shaffer* if there are problems

CMS (Center for Medicare & Medicaid Services) has finalized a rule that will pay Medicaid primary care physicians at the same rate as Medicare in 2013 and 2014, a move that is likely to improve access to care for individuals who receive both Medicare and Medicaid.

<http://www.nslc.org/index.php/tag/dual-eligibles-2/>

Technology—The Hot New Topic

iPad Use in the Disability World

The Apple iPad has gained much recognition in recent years not only to the general public but to the disability world.

The Apple iPad is a technological device many people view as a type of new plaything, although for many people with disabilities it represents a functional tool with the potential to assist them. The tablet is also, generally speaking, is much less expensive than computers and more portable than other gadgets specifically designed to help disabled people speak, read or write. The iPad is increasingly used as a portable communication device by people with disabilities related to communication, as the tablets have the capability of providing access through a variety of input and output media, including voice, virtual keyboards, pictures, symbols, and video. Free applications for use with children, youth, and adults with aphasia, autism, and stroke have been developed and are available for download. In addition, the iPad has received positive reviews from individuals with visual disabilities who have used it, as the device is touch controlled and has a voice function.

The iPad gives individuals with disabilities an opportunity to finally “fit in” with their peers. They can use their device as a functional tool that may be considered as “cool” to the general public but serves them well for the purpose intended. “It gives dignity back to people who are more disabled.”

Here are four ways that touch devices are changing the lives of people with disabilities:

- 1. As a Communicator:** The cost of comparable devices using touch-to-speak technology usually runs up into the thousands of dollars. iPads make for a much cheaper, simpler, way for users to communicate effectively.
- 2. As a Therapeutic Device:** Utilizing the touch screens can help fine-tune motor skills, making it easier to learn other tasks.
- 3. As an Educational Tool:** You can find apps that cover everything from simple math and learning tools up to learning how to read in foreign languages. Tablet apps run the full gamut.
- 4. As a Behavior Monitor:** A number of apps exist that allow parents, therapists and guardians to monitor, record and track behavior.

iPad Touch apps for individuals with special needs: <http://www.scribd.com/doc/29172122/iPod-touch-Apps-Accessories>

iPad Accessibility: “iPad includes an amazing screen reader along with other innovative accessibility features that make it easier to use for those who are blind or have impaired vision.”

Please take a moment to review the article in the NY Times of a boy who depends on a respirator and struggles to make even the slightest movements — he has had a debilitating motor-neuron disease since infancy. In Brooklyn, New York, a nearly paralyzed boy, who cannot talk, uses an iPad to tell his mother what he wants to be for Halloween. Over the years his parents had tried several computerized communications contraptions to give him an escape from his disability, but the iPad was the first that worked on the first try.

Since its debut in April, 2010 the iPad has become a popular therapeutic tool for people with disabilities of all kinds, though no one keeps track of how many are used this way, and studies are just getting under way to test its effectiveness, which varies widely depending on diagnosis. http://www.nytimes.com/2010/10/31/nyregion/31owen.html?_r=0

Virginia’s Dept. of Ed. Technical Assistance Center did a study with students using iPads. When the iPad was introduced to students with severe intellectual disabilities (many with limited motor skills, speech and language deficits, sensory impairments and developmental delays) the response was phenomenal! The iPad allowed for multiple learning opportunities for all of our students regardless of their disabilities. When used as communication device it allowed for quick easy access to communication boards which could be changed by teachers on the spot for any situation. This was very important because students with severe intellectual disabilities learn best when a teachable moment presents itself.

This article can be reviewed at: <http://www.ttacnews.vcu.edu/2011/09/use-of-the-ipad-for-students-with-significant-intellectual-disabilities/>

IN THE STATE OF **NEW MEXICO**, we have some exciting projects that are embracing the opportunities that exist with this device with the deaf and hard of hearing population.

New Mexico Commission for Deaf & Hard of Hearing Launched an iPad Pilot Project

The iPad Pilot Project is a component of the NMCDHH's Telecommunications Equipment Distribution Program (TEDP.) The Telecommunications Access Act [63-9F-1 to 63-9F-13 NMSA 1978] requires the New Mexico Commission for Deaf and Hard of Hearing (NMCDHH) to provide the specialized telecommunications equipment program.

"New Mexico is bringing functional equivalency to a higher level by launching a pilot to distribute iPads," said Ellen Roth, Executive Director, "the iPad is the first device in 20 years that is equally accessible for the Deaf, Hard of Hearing, Speech Disabled and Hearing. The addition of this pilot will allow for more consumers than ever to communicate on the go, just like their peers."

The New Mexico iPad Pilot project launched in January 2013. The project distributed 25 4th generation wifi only 16GB iPads to Deaf, Hard of Hearing, Deaf-Blind and Speech Disabled users.

The iPads were pre-loaded with specific telecommunications and communications applications specific to the individual groups. In addition, tech support was provided via one-on-one trainings at the Commission for Deaf & Hard of Hearing or via email with our distributor, Teltex Inc (www.teltex.com)

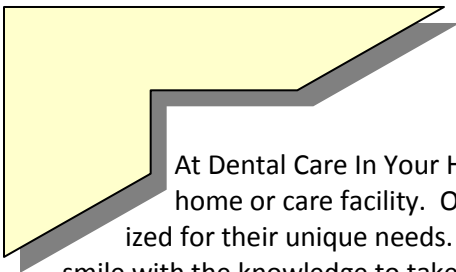
To participate, individuals had to attend monthly focus group meetings, complete monthly surveys and actively test the suite of apps pre-loaded on the devices.

The benefits of this program include the ability to not only provide versatile mainstream devices, but also provide free and paid apps that provide equal access to communication. A device and apps that may have been cost prohibitive for some families, is now available and extremely useful.

The Pilot has been such a success that the program will become a permanent part of the Telecommunications Equipment Distribution Program after July 1st. Information on the program will be available after June 15th by visiting www.cdhh.state.nm.us/iPad.aspx

If you have any other questions or need more information, please feel free to email: ShannonS.Peinado@state.nm.us

Over the past several years, we have clearly been able to see the progress and benefits of the use of this specific technology.



Dental Care in Your Home, Inc. Services at Home

At Dental Care In Your Home Inc. we see homebound pediatric, adult and geriatric patients in their own home or care facility. Our goal is to provide our patients with the highest quality dental care personalized for their unique needs. We look forward to meeting you and helping you to have a healthy, comfortable smile with the knowledge to take care of it daily.

If you have any questions concerning the services they provide or the availability of an appointment or to schedule an appointment, please contact:

Dental Care In Your Home
P.O. Box 65310
Albuquerque, NM 87193-5310
Phone: 505-615-0951
Fax: 505-792-6737

<http://www.dentalcareinyourhome.org/Services.html>

Family Spotlight: The Salazar's

Hello. My name is Cathy Salazar. I am on the Medically Fragile Family Advisory Board, the FAB. My husband Robert and I have 9 children and 1 grandchild. The 3 oldest are my birth daughters, and are 25, 24, 21, and my 4yr old grandson is the son of my 24 yr. old daughter. My 6 youngest children are all adopted out of the foster care system when we were foster parents. My 2 son's are 16, and 15 and deal with behavioral health issues from being drug exposed prenatally. My 12 yr. old daughter just went on the DD waiver and deals with Fetal Alcohol Syndrome. My 13, 8 and 5 year old daughters all participate in the Medically Fragile Program. My 13 yr. old is on the traditional waiver, my 8 yr. old just went back on EPSTD and my 5 yr. old is on Mi Via.

We are a very busy family. All 9 kids plus my grandson all live at home. They are in College to Pre School. My parents and 2 sisters are very much part of how we make this all work. We have kids in all kinds of therapies. We go to behavioral health therapy, occupational therapy, and deal with homebound school teachers and therapists. I participate in 5 IEP's every year for my kids.

As a family we like to travel. When our children were younger we used to travel all over the country every summer. Now that some of them are young adults, and our 13 year old can not travel anymore, we take smaller trips with different kids at different times. It makes it less hectic and we can try to do things that are age appropriate so they enjoy their time.

One of the issues that has come to the fore front of disabilities, is the use of iPad's. Some will see the iPad as a toy. But we have first hand experience with the iPad as a tool for two of our Medically Fragile Children. Our 13 yr. old has a brain injury from being shaken as a 4 month old and uses the iPad with her teacher to access programs that help with cause and effect. She can use head switches to activate activities on the iPad. My 8 yr. old is part of pilot study thru the Commission for the Deaf and Hard of Hearing. They are testing how iPads enhance the lives of people with disabilities. They are specifically looking at communication. My 8 yr. recently spent 5 weeks in the hospital and was able to use her iPad to text message her siblings, FaceTime with me and my sisters, and continue to do her school work with her class. One of the mornings I was not able to get to the hospital as early as usual and she was able to FaceTime with me while the nurses were in her hospital room. They were able to go over some information with me and she was able to get some comfort by seeing and hearing me. I think that the iPad as a tool for people with disabilities will be invaluable. I have seen the difference it can make for my children.

I feel very lucky to have the support of the Medically Fragile Case Management Program. When we adopted our children, we knew that they were born with genetic issues or had suffered abuse, or had been exposed to drugs. But they were still our children and are as loved and cared for as if they were our birth children. It is a lot of work, and I am tired a lot, but would not have it any other way.

The Arc of NM "Dream Big" Summit on Social Equality and Arc Conference—2013

June 14-15: Save the dates and join us in Albuquerque, NM for the 2013 Summit on Social Equality and Arc Conference from June 14-15 where we'll be Dreaming Big alongside the people with intellectual and developmental disabilities. Come to Albuquerque to discover new ways to keep you moving forward towards your goal! Join hundreds of individuals, advocates, families, and professionals in the fields for two days of informative sessions, fun events and opportunities to interact with other people who also Dream.

Registration Deadline : Friday 17, 2013

To Register : <https://www.arcnm.org/event/dream-big/>



Family Advisory Board (FAB) Connections

Over time, the Medically Fragile Family Advisory Board has tried to come up with suggestions and solutions as to how we can reach out to families locally but also in different regions. All of us have the daily demands of family life. Everyone's time is limited. With all that being said, all of us still value the connections that are only had with similar life experiences. Speaking on behalf of your advisory board in making the effort to meet with many of you, they would like to extend themselves to you while you are in the metro area to ease the sense of isolation being away from home. Many of you have doctor appointments in Albuquerque or unforeseen hospitalizations. It is important to all of us that you feel you have the emotional support not only when away from home but at all times. Please feel free to contact your Case Manager if you would like a friendly visit. They can contact me to help to facilitate this. Or, if you so desire, you can also contact me directly.

Lynn Griffin: legriffin@salud.unm.edu c) 505-934-1350

Also, please take a moment to view a webinar the FAB recently did for schools and home health agencies.

The Medically Fragile Program appreciates all of their time and effort set forth in [making a difference for all families.](#)

Webinar link.: <http://cddunm.adobeconnect.com/p8e1sq4oiw0/>

Staying Connected as a Couple

Individual challenges and couples' challenges

The impact on a marriage of having a child with special healthcare needs is affected by each parent's own adjustment, the flexibility of their marriage, and their access to outside supports. Often a marriage can improve a great deal through successfully handling individual and couples' tasks, along with gaining additional resources.

Individual tasks are emotional challenges that need to be managed on a personal basis. While your partner may help you with these tasks, he or she cannot do them for you. Common individual tasks include:

- ◆ Managing grief
- ◆ Maintaining perspective
- ◆ Protecting a corner of life for yourself
- ◆ Finding sources of strength
- ◆ Coping with uncertainty and fears of future
- ◆ Managing guilt, fear and shame
- ◆ Finding healthy support outside of the marriage
- ◆ Finding meaning in the special healthcare needs experience



<http://www.cysticlifef.org/downloads/marriage.pdf> by Lisa C. Green

There is no doubt your life has become far more complicated caring for a child with special healthcare needs and intellectual disabilities that may effect family dynamics that can cause or widen existing cracks in marriages. The care and coordination can be very time consuming. Many times marriage gets put on the back burner. Always try to remember to care for your marriage as well as your child. Having a "date night" to maintain a romantic connection is important. Being a good parent doesn't always equate to being a good partner. It is important to remain a team, being "parenting partners". It is important to recognize everyone's grieving process and emotional responses will be different and work with one another through that process. Having a vision for the future to make sure you are both on the same page is equally important. Finding balance will help you share the joys and challenges that exist.

Many times you may feel you are alone. Many families are "living it" and dealing with the daily struggles that exist. There maybe more natural supports than you are aware of. Try to explore those options and be open and receptive to them. Outside relationships with others can be helpful, whether it be for support or enjoyment.

"Try to remember to work smarter, not harder."

Other reading material "Married with Special-Needs Children: A Couples' Guide to Keeping Connected"

8th Edition

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mfcmp/](http://cdd.unm.edu/mfcmp/)

History of the Medically Fragile Waiver: This was the first Waiver in NM passed in 1985. We can be thankful for Katie Beckett Law which allowed us to pursue in our state.

Katie Beckett Law: *The Legislation That Bears Her Name*

At 5 months of age, encephalitis left Katie Beckett spending most of her early years in the hospital. Her insurance had been exhausted. Medicaid refused to pay for her care at home even though it could be administered at one-sixth of the cost. Her mother worked tirelessly and succeeded in 1981 bringing it to the attention of President Ronald Regan. When she was 3, doctors cleared her to go home with proper supports — she still needed to be on a respirator 12 hours a day. The legislation was signed by Ronald Reagan in 1981, it became known as the “Katie Beckett Waiver” so all children with disabilities could receive Medicaid supports. Katie died in recent years at the age of 34. We are forever grateful for her mother’s hard work and hold her memory of Katie dear to our hearts for what exists for all children who are medically fragile and who have disabilities today.

Current issues associated with medically fragile waivers - state and federal waiver programs were not designed with the supports needed for the adult population, over the age of 21. As children with significant medical needs are living longer due to technology and parents good care, the waiver can not meet many of the needs of the adult issues that exist. As Katie’s mom pursued in home services for her daughter, we as the parents of today, need to pursue the current issues that exist in building the future for our children.

Resources

KIDS BOWL FREE

Register for your state and location and receive 2 free games of bowling every day all summer long for registered children during the summer months.

<http://www.kidsbowlfree.com/>

GENETICS HOME REFERENCE

A website that contains a comprehensive “Guide to Understanding Genetic Conditions” with basic information about genetics in a clear language and links to online resources.

<http://ghr.nlm.nih.gov/handbook>

ONLINE TOY STORES FOR CHILDREN WITH SPECIAL NEEDS

An online toy store for children with special needs has a list of stores that sell toys geared toward children with special needs.

<http://www.friendshipcircle.org/blog/>

POSITIVE BEHAVIOR INTERVENTIONS AND SUPPORTS

PBIS from Preschool to High School:

A Conversation about Implementation

The Technical Assistance Center on Social Emotional Intervention for Young Children (TACSEI) recently hosted a webinar, *Positive Behavior Interventions and Supports from Preschool to High School: A Conversation about Implementation*, which is now available for viewing online. The webinar features a discussion with Glen Dunlap, Lise Fox, and George Sugai on the key elements of Positive Behavior Interventions and Supports (PBIS) and implementation features within early childhood programs and K-12 schools.

[http://www.challengingbehavior.org/explore/
webinars/8.24.2012_webinar.htm](http://www.challengingbehavior.org/explore/webinars/8.24.2012_webinar.htm)

TWIST ‘n WRITE

The Twist ‘n Write pencil is anew model specifically designed to fit smaller hands. A thick 2mm pencil lead never needs sharpening. The wishbone shaped design forces the school-taught “tripod” position. It is great for those with special needs (carpal tunnel, arthritis, ADHD and many more). It is being sold at Staples, Walgreens, Office Depot, CVS, Office Max and Amazon for less than \$2.00. For more information visit:

<http://penagain.com/twistnwrite.html>.