

Spring 2010
Edition 4

Medically Fragile News

Connected



Editor: *Lynn Griffin*

Family Picnic

August 2009

Good times at the first family picnic at Manzano Mesa Multigenerational Center Water Sprayground!!! More to come in June! Flyer enclosed for the upcoming event. Please join us for an evening of fun and time to get better acquainted!



University of New Mexico-Health Sciences Center-Center for

University Centers for Excellence



FAMILY ADVISORY BOARD (FAB)

A Family Advisory Board (FAB) was established in July of 2009. We have a very cohesive, productive group who have accomplished a lot over a short period of time. Some of the accomplishments are as follows.

- A VISION AND MISSION STATEMENT WAS ESTABLISHED:

VISION:

Voices of families leading the way...

Advising and working with families and professionals by caring and supporting individuals who are medically fragile.

MISSION STATEMENT:

The mission of the Family Advisory Board (FAB) is to improve the quality of life for individuals who are medically fragile and their families.

- ~ Using a family centered approach to care, we will:
- ~ Advise on development of policy
- ~ Facilitate access to supports
- ~ Improve delivery of services

MEDICALLY FRAGILE WAIVER: *Discussions occurred on the possible changes*

- Clients levels of care may change due to parameter changes
- Psychosocial counseling will include Behavioral Supports
- RIGHTS and RESPONSIBILITIES document was revised
- Reviewed, as a committee, the rewrite of the Medically Fragile Waiver and members submitted suggestions of changes to be considered
- Developing a respite program for families
 - ⇒ Currently working with Casa Angelica for respite. It will not be available by reservation, only when a vacant bed becomes available
 - ⇒ Also working with ARCA as a provider to establish respite in foster homes. ARCA is a metro area service provider agency. This would also allow families throughout the state access to the service, even though the homes are located in the Albuquerque area.
- Included as part of the menu of services for the Medically Fragile Waiver this year will be \$1000.00 to purchase goods/services for specialized Medical Equipment not paid for through the Salud
- No changes to Respite: 336 hours of respite per year will be maintained

MISCELLANEOUS:

- Reviewed and changed a few of MFCMP annual survey questions. We would like to stress the importance in your participation in the future. If we don't hear from you, we're uncertain on areas we can improve. Compliments are always welcome also!
- Discussion on our Family Networking meetings. The group felt with the busy schedules kept by all of you, it might be best to keep the brown bag lunches to quarterly meetings. Our attendance typically is with a small group. We look forward to our group expanding.
- Revised a parameter criteria letter going out to families to make it more family friendly to those receiving EPSDT services of what the changes may occur.
- Working with and reviewing our new Social Networking site while in development stages by our LEND student. We want to thank all of you who participated in the survey.



October 6-8, 2010

SW Disability Conference's main conference theme this year is:

- * ADA at Forty: Looking Ahead to 2030
- * The Impact of Technology on Improving the Quality of Life for People with Disabilities
- * Improving the quality of Life of Children with Disabilities: What Works, What Doesn't and how to Make it Better

MFCMP will be presenting at the conference:

- ⇒ Case Managers will be presenting the MFCMP Parameter guidelines
- ⇒ A family panel will be assembled from our FAB to participate. Topic of discussion will be how the program has improved the quality of life for the families and the individuals.

A limited number of conference registration scholarships are available for New Mexicans with disability, their personal care attendants, or immediate family members who, because of financial considerations, would otherwise not be able to attend. Scholarships support conference registration fees.

To register or for more information visit the website at: <http://cdd.unm.edu/swconf>

SOCIAL NETWORKING SITE Update

We had a LEND student working with our program this year for her leadership project. Many of you may have spoken to her on the phone when she was conducting a survey. Our student surveyed many families and we were encouraged by the response that families are eager to participate in a Social Networking site. This has been one of her goals. Discussions occurred on putting all pertinent information; (i.e. equipment exchange, meeting notices), all on the networking page. All of this will eventually be posted on our web site with specific instructions on how to navigate it. Suggestions are always welcome, especially from you techie people! This will be a work in progress.

For those of you who unfamiliar with social networking, for many it's a way to connect with other people. For people living with chronic illnesses or disabilities, they play a more vital role. It really allows people to talk and possibly offer advice to someone who might have been experiencing the same things. The advice is not a substitute for medical care. It develops a sense of community, a real-life perspective. Weill Cornell Medical Library in New York has researched how social networks meet the needs of patients living with chronic disease. This is an opportunity to share information amongst families in similar situations.

The Social Networking site is through **Wiggio**. You will receive an invitation to join once I have received your email address which will link you to the site. If you feel you would rather not participate, there will also be a link to unsubscribe.

- * Your name will appear on the top of the page. You can click on it and a drop down menu will appear. This will allow you to edit your profile on how you would like to receive information; i.e *edit my notifications*.
- * There are messages on the board to read on the activity that is occurring

The site has many capabilities if you take the time to explore. Hope you enjoy it and find the value in making those important connections! Please remember to give us feedback.

USEFUL INFORMATION

Wheels for the World: A program of the international disability organization “Joni & Friends” They collect wheelchairs (pediatric chairs are especially needed), extra wheelchair parts, metal canes, walkers, and some other mobility and medical equipment (no electric chairs). They refurbish them, and then distributes them on mission trips to needy individuals in underdeveloped countries.
Contact: Lori Steward 823-9602 stewardfamily@comcast.net

Project Cure: If you have any durable medical equipment or packaged, unopened, medical supplies you no longer use, you can contact two local volunteers who work on behalf of Project Cure: Two people, Charley and Judy Ofelt, will come and pick up the donations. Donations are shipped all over the world, wherever they are needed. Check out the website.
<http://www.projectcure.org/>
Their contact info for ABQ is: 505-296-7728 or email at: coflet@comcast.net
Collection Facility:
5643 B Jefferson St. NE, ABQ, NM 87109
In Las Cruces: Heather Van Doorn 505-532-6005 heathervandoorn@projectcure.org

Adapted literature link at the UCEDD in RI
<http://www.ric.edu/sherlockcenter/resourcelib.html>
click on the here button at the adapted literature section. The story boxes are a cool idea too.

HealthyChildren.org
is the only site backed by 60,000 American Academy of Pediatrics member pediatricians. They are committed to offering the most reliable, up-to-the-minute health advice for proactive parents and caregivers.

organized4kids.com
My IEP Toolkits, WOW! Don't know if you are familiar with this product. They do give bulk rates, if anyone would be interested in getting these, please contact Rose at rose@planaorg.com

Another Wheelchair Recycler Resource: A man in MA named David Heim, who founded The Wheelchair Recycler. He takes old non-working chairs and refurbishes them, for 90% below market value for individuals who cannot otherwise afford a chair. His goal is to help people around the world. His contact info is:
gordon@cpd2.usu.edu

Inspired Birth and Families:
A resource for expecting parents, but they offer numerous classes for those with babies, young kids and even older kids. They also are a wonderful resource for lending library even with toys!
<http://www.inspiredabq.com>

Website for parents with children who have feeding issues and reflux:
A social networking site for parents to connect with other families.
Parent-2-parent.com

Fun for Medically Fragile Families

PICNIC POT LUCK

Bring the whole family

When ? ~ Friday – June 11, 2010

What time ? ~ 6:00 – 8:00 PM

Where ? ~ Manzano Mesa Multigenerational Center

501 Elizabeth St. NE

The facility is just east of Costco at the corner of Elizabeth & Southern, in between Eubank & Juan Tabo, south of Central

A Water Sprayground is located outside at the facility

The water sprayground, a fully automated aquatic play environment where all ages can get wet during the hot summer months. Come prepared with towels and dry clothing for those who may participate. We have access to the indoor facility where we have a room reserved for us. This event will be a POT LUCK. Being this is scheduled during the dinner hour we would like everyone bring a dish to satisfy our appetites and enjoy the festivities at the same time.

Our library (LINC) and other staff will be attending and providing fun activities for our children

Please bring your favorite dish to contribute to this gathering

Please RSVP: Lynn Griffin 272-8801 or legriffin@salud.unm.edu

or if you have become a member of the Wiggiio MF Social Networking group RSVP at: mffamilynetworkinggroup@wiggiomail.com

There is a sign up sheet for your contribution

Hope you can make it! Bring your towels and change of clothes.