Welcome to our first Newsletter, Connected.

We are very excited about establishing our first newsletter. This is the first step in getting our families connected. The Medically Fragile Case Management Program (MFCMP) is committed to bringing you information from many different sources that you may find both helpful and informative.

Our first issue will briefly discuss the importance of a Parent Advisory Council. Our intent was to enclose a clipette of helpful information included in each newsletter.

We plan to have a family and case manager highlight in every edition. Everyone has a story to share. If you would like to do a story about your family, please contact Lynn Griffin. We invite your ideas regarding the contents of the newsletter for future publications and ask for your participation. Someone has suggested having family TIPS included. Please forward any suggestions.

After having spoken with numerous families, many have expressed an interest in networking with one another. Our first meeting has been scheduled; date and time is posted on page 3. The interest in a web based information exchange for families seems to also be of interest. I would like to start collecting email addresses.

Clipette: Did You Know?

Several of our families have participated in CDD’s LEND Program which is an interdisciplinary pre-and post-service graduate leadership training program. One family hosted the student, Laura Ferguson, MD, who she was assigned as a trainee. During the time everyone is getting acquainted, there becomes a focus from the directive of the family for the student to research. This particular family choose which parks were accessible to wheelchairs within a two hour drive.

The National Parks visited by Laura Ferguson were Bandelier: main path is paved and accessible although must climb stairs to peer in cave dwellings, 1/2 mi. in length. Second path down to “Alcove House” is sandy forest soil but quite flat and wheelchair accessible, El Morro: 1/2 mi. path to the rock is paved and has only a slight uphill grade going toward it, Fort Union: Flat gravel paths very assessable, Salinas Pueblo Missions: very wheelchair accessible and flat.

There is a lifetime pass for U.S. citizens or permanent residents with permanent disabilities. Documentation is required to obtain the pass. Acceptable documentation includes: statement by a licensed physician; document issued by a Federal agency such as the Veteran’s Administration, Social Security Disability Income or Supplemental Security Income; or document issued by a State agency such as a vocational rehabilitation agency. The pass provides access to, and use of, Federal recreation sites that charge an Entrance or Standard Amenity. The pass admits the pass holder and passengers in a non-commercial vehicle at per vehicle fee areas and pass holder + 3 adults, not to exceed 4 adults, at per person fee areas (children under 16 are admitted free). The pass can only be obtained in person at the park. The Access Pass provides a 50 percent discount on some Expanded Fees charged for facilities and services such as camping, swimming, boat launching, and specialized interpretive services. In some cases where Expanded Amenity Fees are charged, only the pass holder will be given the 50 percent price reduc-

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- Family Networking Meeting 3

Special points of interest:
- Resources
- Family Highlights
- Enclosure: UNMCH Families as Partners Newsletter

University of New Mexico-Health Sciences Center-Center for Development and Disability
University Centers for Excellence on Developmental Disabilities
Family Spotlight: Meet the Smethurst Family
by Gary and Jane Smethurst

There are also many parent organizations out there. The Information Center for New Mexicans with Disabilities/BabyNet (a part of the Information Center for New Mexicans) helps pregnant women and families with small children gain information to access and utilize medical and support services by educating and providing information.

BabyNet promotes baby wellness by identifying and promoting prenatal and perinatal services as well as helping to reduce the incidence and effects of disabling conditions.

In conjunction with the Information Center we have LINC, our lending library, which happens to be the most comprehensive collection of disability resources in all of New Mexico. You can search the online collection of books, journals, videocassettes and information kits using our ONLINE CATALOG. Other services, including reference librarian assistance, literature searches, interlibrary loan, access to full text articles and Internet information may be accessed using LINC’S ASK A LIBRARIAN service. The staff is available to do any kind of research of articles pertaining to disability issues. If you have any questions regarding our website or their services, do not hesitate to contact them at:

Library and Information Network for the Community Center for Development & Disability
2300 Menaul Blvd, NE
Albuquerque, NM 87107
Phone: 800-827-6380 or 505-272-0281
Fax: 505-272-5280
Email: linc@salud.unm.edu

These resources may be of some help to you. I would be happy to assist you with this information.

Also remember, we as families, are each other’s best resource and support network, and we would all benefit from being connected with each other. We can help you get in touch with an-

Helpful Information by Lynn Griffin

As many of you are now aware, I am a parent of a child with a developmental disability who is now 22 years of age. I have a lot of background in special education from my previous employment. As I began my position as a Family Specialist with the Medically Fragile Program, I realized that even though the needs are different for education and medical, they both follow some of the similar systems. We are always establishing relationships, needing two way communication to build partnerships to have our children’s needs met.

I am available to all of you as a resource. I also work within CDD in the Information Center for New Mexicans With Disabilities/BabyNet which has increased my knowledge of resources available in community.

The Information Center is located at:
Center for Development & Disability
2300 Menaul Blvd, NE
Albuquerque, NM 87107
Hours: 9:00 am until 5:00 pm Monday through Friday
Phone: 1-800-552-8195 or 505-272-8549.

We can also be reached via email at infonet@unm.edu. All of the Resource Specialists at the Information Center are very knowledgeable in resources and service systems.

The Information Center for New Mexicans with Disabilities/BabyNet provides information to individuals with disabilities, families, advocates, therapists and case managers about service providers, support groups and other local state and national resources. The BabyNet information and referral service (a part of the Information Center for New Mexicans) helps pregnant women and families with small children gain information to access and utilize medical and support services by educating and providing information.

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As we look toward the future, the MFCMP is looking at developing a Family Advisory Council to better serve you. The plan would be to meet two times a year. You may have some questions regarding an advisory group which hopefully will be answered below.

I will be scheduling a meeting date and would appreciate some feedback on times from those that are interested in attending. Please contact Lynn Griffin at 505-272-8801 or 1-800-675-2910.

What is an advisory council?
Within your community or state, there may be many opportunities to serve as part of an advisory group to an agency or organization. Their role is to advise— to offer their expertise—they study the issue at hand, collect input from members of the advisory group and perhaps externally from the community, and report back to the larger agency. Your duties on such an advisory group would probably include attending meetings, gathering information from your community, and certainly contributing your own perspective and expertise. The group would also have to prepare recommendations for the agency.

With all my responsibilities, how can I make time for this?
Yes, time is always a problem. You will be asked to attend meetings, and you may need to do research between meetings. Find out how much of a time commitment is involved, and make sure you have—or can make—the time before you say yes. It may help to look at this time commitment as an investment: an investment in your family, in your community, and in yourself.

Can I really make change happen?
Usually, change happens when people become aware of what needs to happen, how it needs to happen, and care that it happens. You can make change happen by getting involved, giving your time and energy to the Council, and helping others to get involved.

Impact of Family Advisory Councils:
~ Giving case managers, MFCMP, and State agencies access to an experienced, diverse group of families willing to serve in a consulting capacity for policy and program development and evaluation.
~ Providing the opportunity to give ongoing feedback that goes beyond what would be learned from satisfaction surveys and focus groups.
~ Offering a forum to develop creative, cost-effective solutions to problems.
~ Having a mechanism for receiving and responding to community input on a regular basis.

The work of family advisory council will lead to:
Services and programs that respond more effectively to consumer needs and priorities.
Increased understanding and collaboration between families and staff.
Wiser use of scarce health care resources.

The information on this page about Parent Advisory Councils was taken in part from:
A PARENT’S GUIDE TO SERVING ON BOARDS AND COMMITTEES, by Sherri Coles.
A publication of…..NICHCY
National Information Center for children and Youth with Disabilities:
PO Box 1492
Washington, DC  20013
1-800-695-0285
e-mail: nichcy@aed.org
URL:  http://www.nichcy.org
And Developing and Sustaining a Patient and Family Advisory Council, by Patty Devine Web-
Useful websites:
Used equipment available for free or for a cost.
Backinuse.com

Pacer Center:
A Minnesota nonprofit organization that provides services without a fee to families of children and young adults with any disability.
Pacer.org

Wrights Law:
Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law, education law, and advocacy for children with disabilities.
Wrightslaw.org

Ability Online:
Is an extraordinary and absolutely free Internet community. Here, young people with disabilities and illnesses connect with all kinds of possibilities.
Abilityonline.org

Wheel Chair Vans
http://www.mobilityvansales.com/usedhandicapvans/new%2vmexico_vansales.html

We encourage your ideas with the content of the Newsletter.
Send us your ideas via email to:
legriffin@salud.unm.edu
Or mail to
UNM Health Sciences Center
Center for Development and Disability
2300 Menaul NE, Albuquerque, NM, 87107.

The best part of life is not just surviving, but thriving – with passion and compassion, and humor and style, and generosity and kindness.  

Maya Angelou

It needs YOU!!!