Medically Fragile News

Happy Holidays!

Wishing you and your family a happy holiday season.

8TH EDITION

DECEMBER 2012

Inside this issue:

SUMMER FUN

Something to take the chill out of the air !

Good times and good connections had by all. Another successful event for our annual summer gathering. We had a good turn out with many new faces joining us!! Look for next years event in the Spring newsletter.

MOM'S NIGHT OUT!! PLEASE JOIN US

The Medically Fragile Family Advisory Board would like to invite you to join us to our **Mom's Night Out.** It a wonderful time to get acquainted, have a few laughs, and let our hair down.

We schedule monthly gatherings at a local restaurant, here in Albuquerque. If you are interested please contact Lynn Griffin:

505-934-1350 *or* legriffin@salud.unm.edu

WELCOME OUR NEW CASE MANAGERERS

Please join us in welcoming Megan Yarbro-Armijo and Maggie Nechvatal, our two new case managers. They are both serving the Albuquerque/Metro area. Both are bringing excellent experience to the MFCMP. We are pleased they are finally here.

University Centers for Excellence on Developmental Disabilities Education,
Research, and Services
University of New Mexico-Health Sciences Center-Center for Development and Disability

My Health-My Decision

Parents assume responsibility for their children with chronic care management along with their pediatricians. When the child becomes an adult, chronic care management is ideally transferred to the young adults and/or caregivers and adult medical providers. The complexities of managing a chronic health care condition transition process for adolescent to young adults begins at the age of 14 as a part of the IEP/504 education transition process but originates and encompasses the healthcare system. Typical transition planning includes post-secondary education or vocational training, adult education, employment, and independent living or community participation. This works well for many youth, but it is inadequate for those who have chronic health conditions. If the individual is capable of directing his or her own care, the individual will need to learn to manage their health and wellness if they are going to succeed in other areas of life identified in the transition plan. It will necessitate managing medications, health status; insurance; medical appointments; hospital stays; and absences from school and work. Some individuals will not be able to make those decisions on their own.

Guiding Questions to Ask in Considering Decision-Making Support Options

In considering what is the right decision making support for a young adults may be, here are some key questions families may ask:

1. What kind of decision is being made?
2. Has the person made a decision like this before?
3. Has the person been assisted to understand the risks and benefits?
4. How big is the impact of this decision in the person's life?
5. How long would the person live with the decision?
6. How hard would it be to undo?
7. Most important: What is the least restrictive level of support that might work.

You're baby's growing up! Decisions to be considered!

Guardianship and Alternatives for Decision-Making Support

Written by: Got Transition Staff with support from Tina Campanella, Quality Trust for Individuals with Disabilities

http://www.gottransition.org/

National Health Care Transition Center

~~~~~~

For information on "informed consent" and health care for individuals with intellectual disabilities. You can access My Health-My Decision, a training module developed by a team of self-advocates with support from the Maryland Developmental Disabilities Administration, to teach individuals how to become more in charge of their healthcare decisions, an agency guide, and a workbook for participants. "Informed Consent for Healthcare Decisions," a related training for families and staff, is also available.

http://myhealthconsent.org/home.html

Reference Points from Pacer Center
Transition points from TATRA
~~~~~~

Family Spotlight: *Meet the Murchio 's*

Hello, my name is Celina Murchio and I am currently a stay at home mom. My husband David and I have been married 15 years. David is a nursing student and will be graduating in December. We have two wonderful boys, Shane is 14 and Nathaniel is 11.

Shane was diagnosed with a benign brain stem tumor at 9 months old which caused him to have both cognitive delays and many physical/ medical needs. Much of his early life was spent in the hospital battling pneumonia. Because of the chronic and reoccurring pneumonia he ended up with Chronic Lung Disease. He had a tracheotomy in 2004 and uses a vent at night. He has amazed us with his courage, strength and positive attitude. Shane is now a freshman in high school and has come so far both cognitively and physically. He is healthy, vibrant and loves to learn, read books from the library and play video games. We are also very lucky to have an 11 year old who is mature beyond his years. Nathaniel loves to help his brother and knows more about medical equipment and the care and work it takes to keep his brother healthy than any kid should have to know.

I can't believe how quickly time has flown by since that first moment we learned our son was special. As parents of a child with special needs we have been through many challenges and know that there are many more to come. But we have Shane to inspire us to never give up, smile despite the hardships and enjoy each moment with each other.

Meet Jason Riggs! PATRICIPATING IN BAND PERFOMANCE

Jason is participating in band at his middle school where there is the belief in inclusive practices where everyone belongs and everyone is welcome!

Jason is a 6th grader at LBJ Middle School. He is in the 6th grade Band and plays the snare drum. The photo is at the Halloween themed concert held this October. If you look very closely you may be able to make out his Gryffindor scarf and Harry Potter glasses. His music therapist, Mary Kay Hoppe who is a "registered and board certified music therapist", is sitting on his right and assisting him playing the drum.

Jason has had a lifelong passion for music and rhythm and Band has been an excellent opportunity for inclusion in middle school. Jason's band teacher Ms. Reese has been very supportive and open to learning what accommodations Jason needs. She recognizes his talent and encourages him. Jason also receives support from his peers. He was cheered on after his first playing test and his peers enjoy his laughter and smiles.

Jason's parents (Harold and Carolyn) and sister (Maryanne) are very proud of him. His parents and nurse help him practice drumming. He has even attempted a couple duets with his sister playing her violin. Harold and Carolyn always advocate for Jason to have inclusion opportunities. Over the years, Jason has participated in many different kinds of classes. This current opportunity in Band is his favorite so far. After the band concert, his family was approached by several people. One father said that his daughter had talked to him about Jason being in her class. Inclusion is not just good for our kids, it is important for everyone. For these peers will grow up to be doctors, case workers, teachers, musicians, and parents (maybe even have a child with special needs themselves) and their experiences with kids with special needs will expand their outlook and help shape the world for kids with special needs everywhere.

The First Hand Foundation is a not-for-profit, 501(c)(3) organization that provides funding so individual children may have access to health care that would otherwise be impossible. Their mission is to directly impact the health status of a young life. In 1995, Cerner founded the First Hand Foundation to directly fund health-related needs for individual children when insurance and other financial resources have been exhausted.

Expenses covered:

⇒ Treatment: Clinical procedures, medicine, therapy, prosthesis, etc.

⇒ Equipment: Wheelchairs, assistive technology equipment, care devices, hearing aids, etc.

⇒ Displacement: Lodging, food, gas, parking and transportation for families of seriously ill children who must travel during treatment

⇒ Vehicle modifications: Lifts, ramps and transfer boards

https://applications.cerner.com/firsthand/

Did YouKnow?

Micahel J. Astrue, Commissioner of Social Security, added 52 new Compassionate Allowance conditions to the list. The Compassionate Allowance Program allows patients with certain diseases to receive disability decisions with in days rather than months or years. The new conditions became effective August 2012.

Apple's Commitment to Accessibility for more than 20 years to assist those with cognitive disabilities. Apple includes assistive technology in its products as standard features at no additional cost. For more information about the many accessibility features built into Apple products, go to:

www.apple.com/education/special-education

Sites that link to sources of FREE iPads:

- Apps for Children with Special Needs: **http://a4cwsn.com/**
- iHelp for Special Needs: **www. Ihelpforspecialneeds.com**
- Lillie's Pad: Your Special Needs resource for the iPad and iPhone

For those of you who are on Mi Via - If the need for an assistive technology device has been identified, it can be included in on your child's budget. For those on the Medically Fragile Waiver you have a $1,000 Specialized Medical Equipment Allowance per ISP cycle built into the budget that can be utilized. Ask your Case Manager or Mi Via Consultant about it.

FYI: PROGRAM UPDATES—A letter went out regarding the role of your Case Manager which is included in the Rights and Responsibilities piece of the ISP. We hope you found it easily understood and family friendly. It was reviewed by your Family Advisory Board with this intent in mind. Families should have received it in the mail several months ago.

PLEASE NOTE: The Family Specialist, Lynn Griffin, no longer has a landline in her office. Her new number to contact her is: **505-934-1350**

ANNUAL SURVEY—The results are back from the annual survey. We wanted to thank all of you who participated. There continues to be a general high level of satisfaction with the Medically Fragile Case Management Program in all aspects of its service, including the assessment process, the individual service plans, the case managers, and the central office. This is shown both by the high average response scores, and the very favorable comments from respondents.

"Wouldn't want to be in any other program.
It's the one area in which we've NEVER been disappointed."

Center for Development and Disability (CDD) Information Network
A Medical Home – What Is It?

A **Medical Home** is not a house, office, or hospital, but rather an approach to providing comprehensive primary care. In a medical home, a pediatric clinician works in partnership with the family/patient to assure that the medical and non-medical needs of the child/youth are met. Through this partnership, the clinician can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family. The American Academy of Pediatrics (AAP) describes the ideal Medical Home as one that provides "**accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care**." Though many Medical Home implementations focus on children with special health care needs, "**every child deserves a Medical Home** “ from:
http://www.medicalhomeportal.org/medical-home

Key components from (http://www.medicalhomeportal.org/medical-home) applicable to Medical Home include:

Family-centered partnership: Trusting, collaborative, working partnership with families respecting their diversity and recognizing that they are the constant in a child's life

Community-based system: Family-centered, coordinated collaborations designed to promote the healthy development and well-being of children and their families

Transitions: Provision of high-quality, developmentally appropriate, health care services that continue uninterrupted as the individual moves along and within systems of services and from adolescence to adulthood, and recognizing that they are the constant in a child's life

Value: A high-performance health care system requires appropriate financing to support and sustain medical homes that promote system-wide quality care with optimal health outcomes, family satisfaction, and cost efficiency.

The CDD Information Center is currently working with the University of Utah-Health Sciences Center to add NM based resources and services to their existing Medical Home website located at:
http://www.medicalhomeportal.org/medical-home . By early next year, you will be able to visit this site and locate our state resources and services by clicking on the NM link. Meanwhile, we invite you to visit the Medical Home website to learn more about the various publications and documents available for parents and families and others.

REMINDER: ALL MEDICALLY FRAGILE WAIVER CONSUMERS FOR INITIAL AND ANNUAL REASSESSMENT:

⇒ Parents, legal guardian or the individual, must provide income information for the initial application to the MF Waiver and for each annual reassessment thereafter.

⇒ This is required even though it does not matter what the parent's/guardian's income is, only the applicant's income. This is a federal regulation.

⇒ The ISD office sends each family/individual a form letter requesting the completion of the form and submission of the form to ISD. There is a deadline date attached to the ISD application.

Be sure that to pay special attention to the mail return date for these forms.

UNM Health Sciences Center
Center for Development & Disability
2300 Menaul Blvd. NE
Albuquerque, NM 87107
Phone: 505-272-2757
Toll Free: 1-800-675-2910
Fax: 505-272-8100

Lynn Griffin
Family Specialist
505-934-1350

Email:
legriffin@salud.unm.edu

http://cdd.unm.edu/mfcmp/

To help ensure that diaper needs are met for our area's low income families, the elderly and those families caring for someone with a disability, LifeROOTS who is a provider agency has partnered with The Diaper Bank of New Mexico. They are collecting diapers to help in this great effort – and are happy to be part of this community effort involving numerous other not-for-profit organizations all working together to help families in need throughout New Mexico.

For more information on how to contribute to diaper bank and to arrange a drop off at their offices, call 505-255-5501.

For more information about the Diaper Bank of New Mexico and the great work they are doing in spearheading this important initiative, visit: www.diaperbankofnm.weebly.com.

~~~~~~

HOW ABOUT THAT FOR INCLUSION! LifeROOTS has introduced a new bilingual "Inclusion Playgroup" licensed program specifically designed to integrate typical children and children with developmental delays -- providing an opportunity for them to play together, interact and practice school skills in a classroom-like setting.

The LifeROOTS Inclusion Playgroups were designed to provide a setting for typical children and those with developmental delays to engage in a number of fun -- and educational -- activities together, including sensory activities and circle time. Playgroups are led by bilingual teachers with expertise in early childhood education of 2 and 3 year olds, as well as experience in special education.

The Inclusion Playgroup program is available at no cost for eligible children enrolled in the Family Infant Toddler (FIT) Program; for children not enrolled in the FIT Program, there is a $10 cost per session. For more information, call 505-255-5501

Resources : Useful Links

Parenting Special Needs Free Online Magazine

http://parentingspecialneeds.org/

~~~~~~

www.HelloGrief.org

Learn and share about grief and loss. Online community includes forums, articles and resources.

~~~~~~

Camp Zone Camp

www.ForeverSibs.org

www.comfortZoneCamp.org

Camp Zone Camp is a place grieving children cam come year after year and obtain tools to help them cope with their daily lives.

Honors the role of siblings through social support and education, thereby decreasing their isolation and anxiety.

~~~~~~

The Starkley Hearing Foundation

www.starkeyhearing foundation.org

Hear now is a national non-profit program sponsored by The Starkey Hearing Foundation that provides hearing aids for people with limited income.

Mini-Miracles: is an adaptive clothing line designed for the special needs child.

www.minimiracles.ca

~~~~~~

Mercy Flight: Southwest offers free flights for those in need. Their mission is "Coordinating free air transportation for children and adults with medical or compelling humanitarian needs."

www.MercyFlightSE.org

~~~~~~

Air Charity Network
877-621-7177 (this number will direct you to the correct Angel Flight organization by the state you are calling from)
www.aircharitynetwork.org

~~~~~~

Transition's Missing Link: Health Care Transition

http://www.ncwd-youth.info/policy-brief-05

~~~~~~

A guide for Understanding the New Healthcare Law

Consumers Union, the publisher of Consumer Reports, has created a consume guide to help you understand your options, including Web resources where you can get additional information.

www.prescriptionforchange.org/guide

www.ConsumerReportsHealth.org/insurance