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# OUTREACH PROJECT MEDICALLY FRAGILE CASE MANAGEMENT PROGRAM



# OUTLINE

- Problem framing
- Research
- Products
- Dissemination



# PROBLEM FRAMING

**Addressing the problem of children who are medically fragile and/or have neurodevelopmental disabilities that have not been referred to the appropriate program.**

**This capstone project is to conduct an outreach program to explain and discuss the medically fragile program to key stakeholders in the community. This will include disseminating informational brochures and referral forms. Part of the outreach will include the population of children who would meet criteria for the medically fragile program and if they do not meet criteria, directing the child to the most appropriate program for them. This would include the developmentally disability waiver/support waiver, early intervention, autism program, etc.**

# LEND OBJECTIVES

- **Competency 1: Family-Centered/Culturally Competent Practice**

- 1.2 Demonstrate an awareness of the primary importance of the family in the life of a child
- 1.3 Demonstrate attitudes/behaviors required for successful family-professional partnership
- 1.5 Demonstrate an awareness/sensitivity to the impact of disability on family
- 1.6 Demonstrate awareness of the benefits of partnership with families at program/policy level
- 1.7 Describe the benefits of a medical home model

- **Competency 3: Knowledge, Skills and Attitudes**

- 3.2 Demonstrate knowledge of the services available through MCH

- **Competency 4: Leadership**

- 4.7 Demonstrate leadership skills in the facilitation of a seminar or meeting

- **Competency 5: Research and Critical Thinking**

- 5.2 Demonstrate skills in access/utilization of electronic information, resources and databases
- 5.3 Gain experience with designing, revising, implementing and evaluating a research project
- 5.4 Demonstrate basic competencies in professional writing
- 5.5 Demonstrate verbal presentation skills including use of PowerPoint and auditory augmentation system

- **Competency 6: Policy and Advocacy**

- 6.3 Demonstrate networking and advocacy skills
- 6.4 Demonstrate an understanding of state and national disability legislation
- 6.5 Demonstrate an understanding of health care funding

# RESEARCH

## **Financial and Psychological Stressors Associated with Caring for Children with Disability**

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4315505/>

### **Abstract**

-Introduction-The magnitude of stress and associated health consequences experienced by caregivers compromises their ability to effectively provide care to children, especially children with disability.

-Results-Compared to children residing in households where caregivers experienced very little or no stress, children with disability were twice as likely to reside with caregivers with high levels of financial stress and almost three and half times as likely to reside with caregivers with high levels of financial stress and very high levels of psychological stress than typically developing children.

-Discussion-Reducing caregiver stress is a critical step to ensuring the best health outcomes possible for children with disability. Children with disability are more likely to live in households where a greater number of stressors affect caregivers. This is an important implication when determining the right interventions to target to the right subpopulations.



# RESEARCH

## Financial burdens and mental health needs in families of children with congenital heart disease

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6105538/>

### Abstract

**Objective-**To examine the financial burdens and mental health needs of families of children with special healthcare needs (CSHCN) with congenital heart disease (CHD).

**Results-**Overall, families of 89.1% of CSHCN with CHD experienced at least one financial burden and 14.9% needed mental health services due to the child's condition. Compared with CSHCN without CHD, those with CHD had families with a higher prevalence of all financial burdens (adjusted prevalence ratio [aPR] range: 1.4–1.8) and similar family member need for mental health services (aPR = 1.3, 95% CI [1.0, 1.6]). Across both age groups, insurance type, activity limitations, and comorbidities were significantly associated with financial burdens and/or family members' need for mental health services.

**Conclusions-**CSHCN with CHD, compared with those without CHD, lived in families with more financial burdens. Interventions that reduce financial burdens and improve mental health of family members are needed, especially among CSHCN with CHD who are uninsured and have comorbidities or activity limitations.

# RESEARCH

## **Raising Children with Special Health Care Needs and the Impact on Family Health**

[https://www.kdheks.gov/shcn/download/Family\\_Health.pdf](https://www.kdheks.gov/shcn/download/Family_Health.pdf)

Special points of interest: Families experience daily struggles that impact all aspects of their lives.

Parents are not the only ones impacted by a child's SHCN. Siblings feel the impact as well. Physical and emotional health needs are often overlooked by parents as they focus on their child's needs. Having a strong support system or network can make all the difference for families of children with SHCN.



# PRODUCT

**-LEND PowerPoint Presentation**

**-Brochure**

**-Referral form**



# DISSEMINATION TO STAKEHOLDERS

- Early Intervention
- Elementary Schools
- Therapy agencies
- CYFD
- Pediatrician/Medical provider offices
- UNM Residents (Hospital liaison)
- UNM-Nursing programs, PT/OT/SLP/Social Work graduate programs (Jennifer and Sue)
- Webinars/Conferences
- Managed Care Organizations
- LEND

# **MEDICALLY FRAGILE CASE MANAGEMENT PROGRAM (MFCMP)**



CENTER FOR  
DEVELOPMENT  
& DISABILITY



# Objectives

- Understand services provided through the medically fragile case management program
- Identify individuals that would likely qualify for the medically fragile case management program
- List two ways to refer an individual

# Beginnings

- Medically Fragile Waiver was started in 1984 by a mother of a medically fragile child who wished to care for her daughter in her home rather than an institution
- The Medically Fragile Waiver was developed to provide specialized home-based services to 25 children who otherwise would have been served in hospitals or state institutions.
- The Medically Fragile Waiver was approved through the 1984 New Mexico Legislative Session and began in 1985.





# MISSION STATEMENT

Our mission is to support the desire of the family to have their child who is medically fragile live with them at home.



# Definition of Medical Fragility

- Medically Fragile is defined as a chronic physical condition which results in a prolonged dependency on medical care for which daily skilled (nursing) intervention is medically necessary and is characterized by one or more of the following
  - Respiratory involvement along with ventilator dependence
  - Neurological problems, such as cerebral palsy, uncontrolled seizures, spastic quadriplegia and anoxic brain damage.
  - Nutritional problems, such as requirement for TPN, gastrostomy and jejunostomy feeding tubes.



# Medically Fragile Criteria

- Children qualify for the program based off of their medical fragility assessment factors, not necessarily their diagnosis.
- Children must also meet a developmental delay criteria

## COMPREHENSIVE SCORING

- Medications
- Medical Care/Supervision
- Nutrition and Feeding
- Respiratory
- Neurological
- Complex medical/skilled care treatments
- Medical impact based on ability for self care
- Family Support Issues

# Level of Care

- A comprehensive system to determine how medically fragile an individual is.
- The more medically complex they are the more in home skilled care they need.
- Ventilator dependence is the highest level of care-maximum 112 hours a week
- Level 1-40 hours a week
- Level 2-30 hours a week
- Level 3-20 hours a week

# Waiver and Non-waiver EPSDT

## MEDICALLY FRAGILE WAIVER

- Do not meet income requirement to receive Medicaid
- Must meet criteria
- Must have level of care performed and approved through the Income Support Division (ISD) process can take 2-6 months
- Received Medicaid based off of their medical fragility regardless of income

## MEDICALLY FRAGILE NON-WAIVER EPSDT

- Already receiving Medicaid
- Must meet criteria
- Services can start immediately once child meets criteria
- Family must continue to meet income guidelines for Medicaid. If this is at risk family would be referred to the medically fragile waiver



# Services Provided

## MEDICALLY FRAGILE WAIVER

- Medicaid
- Ongoing nurse case management
- In-home skilled care (nursing, home health aide)
- In-home respite care
- Behavioral counseling for client (if applicable), parents and siblings.
- Specialized Medical Equipment Fund
- Environmental Modifications
- In-home nutritional counseling
- PT, OT, SLP services for over 21 clients

## MEDICALLY FRAGILE NON-WAIVER EPSDT

- Ongoing nurse case management
- In-home skilled care (nursing, home health aide)



# Nurse Case Management

- Albuquerque Metro Area (7 RN CMs) + Satellites (6 total RN CMs located in Artesia, Farmington, Las Cruces (2), Santa Fe and Portales) serve ~ **380 medically fragile individuals**
- Face to face contact - at least **every other month** in the home, therapy agencies, school and/or at medical appointments (\*Since COVID all visits have been held over **Zoom every month**)
- Phone visits provided the months not seen face to face
- Liaison between the interdisciplinary team (IDT)
- IDT = health care team, MCOs, community providers, Family Infant Toddler (FIT) program and public school systems.
- Communicates **monthly** with
  - Care coordinators from the MCO's (Blue Cross, Presbyterian, Western Sky Community Care)
  - Nursing agencies (Children's Home Healthcare, Harmony Home Health, Thrive Skilled Pediatric Care)
- Level of care assessments on Mi Via clients on an annual basis



# Nurse Case Management

- Advocates for the individual and family
- Facilitates identification of priorities and concerns of the family
- Assists with access to durable medical equipment (DME), medical and therapy providers, schools (can attend IEP's if requested), arrange counseling services, connect with community resources and various other ways to support families
- Assists with transition planning (graduating from early intervention, changing schools, changing waivers, guardianship, transition to adulthood)
- Provides opportunities for families and the individual to enhance their own abilities to undertake case management functions

# MFCMP Family Specialist

- The role of the Family Specialist is integral to the provision of family centered care.
- The Family Specialists connects families through home visits, phone calls, regional site visits, emails and the newsletter; facilitates the FAB – Family Advisory Board; works with RN/CMs.
- Organizes activities for medically fragile individuals and their families in the community.





# Referral Process

- Many referrals come directly from hospitals (NICU/PICU)
- Pediatricians, early intervention, schools, MCO's, CYFD, self-referrals.
- Referrals are pre-screened for appropriateness
- Slots for the Medically Fragile Waiver are allocated by the Developmental Disabilities Support Division (DDSD) at the Department of Health.

# Referral Process

- Individuals who are applying to the Medically Fragile Waiver (MFW) must be diagnosed by the age of 22 years with the condition that makes them medically fragile.
- Individuals must meet eligibility for Intellectual/developmental delays

# Across the lifespan

- Medically Fragile Waiver services will continue through the client's lifespan as long as the individual continues to meet criteria of medically fragile and developmental disability
- Level of care assessments are performed annually, to determine if level of care needs changed
- If individual no longer meets criteria they graduate from the medically fragile program, this may include transition to another program or resources



# For More Information

**CDD website:**

**<https://unmhealth.org/services/development-disabilities/programs/other-disability-programs/mfcmp/>**

**NM Department of Health website:**

**<https://www.nmhealth.org/about/ddsd/pgsv/mfw/>**

**Contact the Medically Fragile Case Management Program  
directly (505) 272-2910    CDD-MedFrag@salud.unm.edu**

# REFERENCES

- Goudie, A. Narcisse, M. D. Hall, D. Kuo. Financial and Psychological Stressors Associated with Caring for Children with Disability. *Fam Syst Health*. 2014 Sep; 32(3): 280–290. Published online 2014 Apr 7. doi: [10.1037/fsh0000027](https://doi.org/10.1037/fsh0000027)
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\*All Photographs were used with parental consent