

# Medically Fragile Non-Waiver Family Handbook

2300 Menaul Blvd. NE Albuquerque, NM 87107 505-272-2910 Toll Free 1-800-675-2910

2024 Edition

# **CIRCLE OF SUPPORT**

Welcome to the Medically Fragile Case Management Program. We exist to help individuals who are medically fragile live at home with their families and thrive in their communities. Our Nurse Case Managers help clients and families navigate complex systems, identify resources and supports, and anticipate future needs. Below are important team members and their contact information.

MFCMP Nurse Case Manager:	
Phone:	Email:
MCO Care Coordinator:	
Phone:	
Nursing Agency:	
Clinical Supervisor:	
Phone:	Email:

### Medically Fragile Case Management Program (MFCMP)

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The purpose of this handbook is to provide families with information regarding the Medically Fragile Case Management Program (MFCMP) and other information that may be helpful to families of individuals who are medically fragile.

The MFCMP is part of the University of New Mexico (UNM) and the Center for Development and Disability (CDD). The CDD is New Mexico's University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD).

The MFCMP contracts with the New Mexico Department of Health (DOH)/Developmental Disabilities Supports Division (DDSD) and the three New Mexico Medicaid managed care organizations to provide nurse case management services to individuals who are medically fragile.

The MFCMP provides services through the Medically Fragile Waiver (MFW) program and the Medically Fragile Non- Waiver Early Periodic Screening Diagnostic Treatment program (MFE). Each individual who receives services through either of these programs is assigned a case manager who is a registered nurse. The MFCMP provides nurse case management services across the state of New Mexico. The main MFCMP office is located in Albuquerque, with satellite offices in Artesia, Portales, Farmington, Las Cruces and Santa Fe.





### What is the Medically Fragile EPSDT Non-Waiver Program (MFE)?

The Medically Fragile EPSDT Non-Waiver Program (MFE) is a program that provides services to individuals under age 21 who have been determined to have both a medically fragile condition <u>and</u> a developmental disability or are at risk for developmental disability. The MFE provides support to families by providing assistance to individuals in their homes.

#### What makes a person eligible?

To qualify for services, the individual must the criteria for medical fragility.

For medical eligibility, a person who is medically fragile needs ongoing skilled nursing care, evaluation and decision making due to a complex chronic medical condition.

#### What services are available to EPSDT Non-Waiver clients/recipients?

All individuals who qualify for MFCMP MFE services already receive Centennial Care (Medicaid) benefits through their MCO.

In addition to the noted EPSDT benefits, individuals on the MFCMP are eligible for in-home skilled care through RN/LPN services or in-home support with activities of daily living through home health aide services with RN oversight. All services are dependent on the availability of providers.

MFCMP SERVICES FOR MFE INDIVIDUALS UNDER 21 YEARS OF AGE		
Ongoing RN/Case Management (OCM)	With at least monthly contact, a registered nurse case manager supports the individual and their family in their home and community. They provide assistance in navigating complex systems, identifying resources and supports, and anticipating future needs.	
Access to In-Home: Registered Nurse (RN)	In-home care to allow the primary caregiver a limited leave of absence from providing care.	
Licensed Practical Nurse (LPN) Home Health Aide (HHA)	All services must fall in the scope of the service provider.	

Note: All services must be appropriate and medically necessary and dependent on availability of providers.

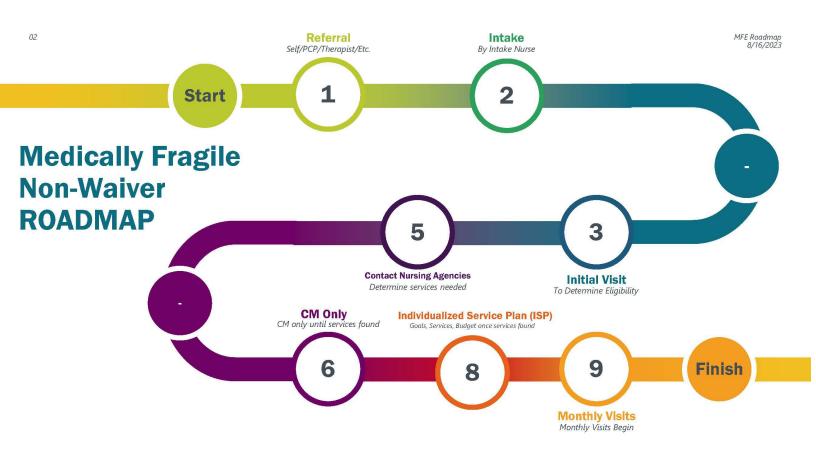


## **Medically Fragile EPSDT Non-Waiver Program (MFE)**

The MFE process begins with a referral and phone intake to determine if an individual meets criterion. A referral can be accessed at our website: <a href="https://unmhealth.org/services/development-disabilities/programs/other-disability-programs/other-disability-programs/mfcmp/">https://unmhealth.org/services/development-disabilities/programs/other-disability-programs/mfcmp/</a>

If determined to meet criteria, the individual's case is assigned to a Nurse Case Manager who sets up an initial visit.

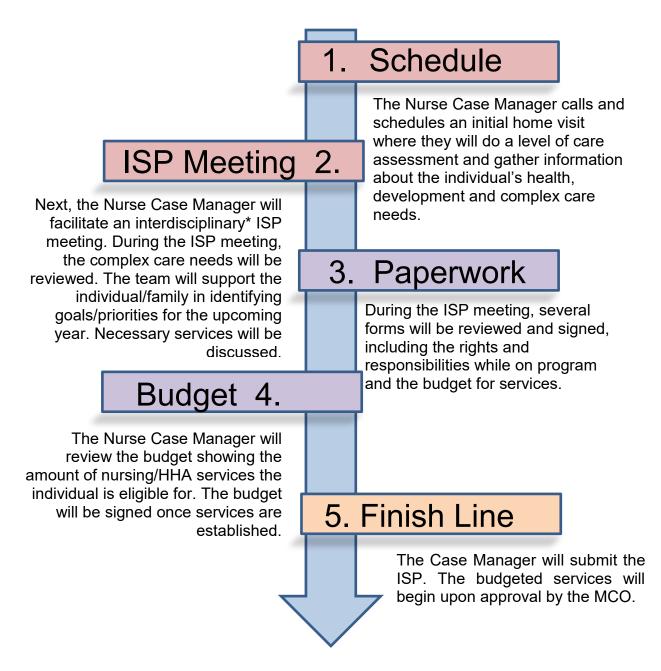
The following roadmap, assists individuals, families and team members to see where they are in the process.





### **Medically Fragile EPSDT Non-Waiver Program (MFE)**

Individualized Service Plan (ISP) Process



Congratulations! You have finished the ISP process.

**\*Who is invited to the ISP?** – The ISP is an interdisciplinary team meeting with the individual and family. The individual must be present. The Nurse Case Manager invites the MCO Care Coordinator and the nursing agency to the meeting. The individual/family are welcome to invite anyone else they feel should be a part of the meeting.



### **Centennial Care**

Centennial Care is the name of the New Mexico Medicaid program. Centennial Care services include physical health, behavior health, long-term care and community benefits.

Centennial Care services also include Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefits for individuals who are under 21 years of age.

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit is the Medicaid health care benefit package for children and adolescents. The EPSDT benefit provides comprehensive and preventive health care services that are medically necessary.

EPSDT is made up of the following screening, diagnostic, and treatment services:

- Early: Assessing and identifying problems early
- **Periodic**: Checking children's health at periodic, age-appropriate intervals
- **Screening**: Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
- Diagnostic: Performing diagnostic tests to follow up when a risk is identified, and
- Treatment: Control, correct or reduce health problems found

EPSDT benefits for individuals under age 21 include physical therapy, occupational therapy, speech language therapy and pathology services when determined to be medically necessary. These services are provided through the individual's MCO.

Eligibility for all Medicaid programs requires that individuals meet certain federal guidelines. These include citizenship, residency and income requirements.

### Managed Care Organizations (MCOs)

A managed care organization is an insurance company that contracts with providers and medical facilities to provide healthcare services to its members. Centennial Care services are provided by managed care organizations (MCOs). Each person covered by Centennial Care selects one of the MCOs to provide their Centennial Care services. Currently, the three MCOs offering Centennial Care coverage are: Blue Cross Blue Shield of New Mexico, Presbyterian Health Plan, and Western Sky Community Care.

Care coordination is an important service that is provided through the Centennial Care Medicaid MCO. Care coordination is available to all Centennial Care Medicaid members. Care Coordinators work with members and their care team, including their doctors and MFCMP Case Manager. Care Coordinators assist with navigating Centennial Care healthcare services (such as doctor visits, behavioral health, vision, dental, medical transportation and medications) to ensure services are coordinated and accessible when necessary.



# **Turquoise Care Is Coming!**

Turquoise Care will begin July 1, 2024, replacing what is currently called Centennial Care, as the new, New Mexico Medicaid Managed Care program.

Open enrollment to choose an MCO is April 1 through May 31, 2024. Available MCOs include:

Blue Cross Blue Shield of New Mexico



🖄 PRESBYTERIAN

**BlueCross BlueShield** of New Mexico

- Molina Healthcare of New Mexico
- Presbyterian Turquoise Care





For more information and answers to FAQs regarding Turquoise Care visit: <u>https://www.hsd.state.nm.us/turquoise-care/</u>

### Changing MCOs Outside the Open Enrollment Period

From HSD's website - How to Switch MCOs:

Per State regulation 8.308.7.9 H NMAC, HSD allows a member to change his/her Managed Care Organization (MCO) selection outside of the annual recertification period for cause, such as but not limited to: poor quality of care, lack of access to covered benefits, or lack of access to providers experienced in dealing with the member's health care needs.

### Requests to change your MCO must be sent in writing to:

New Mexico Human Services Department Medical Assistance Division P.O. Box 2348 Santa Fe, NM 87504.

For more information, please call the Medicaid Member Services Call Center at <u>1-888-997-</u> <u>2583.</u>



### When you disagree with an MCO's decision

### **Requesting an Appeal**

- If you disagree with a decision made by the MCO about a benefit, you may file an appeal. This can be a denial, reduction, limited authorization, suspension or termination of a new, or currently being provided, benefit.
  - Information on how to request an appeal is found on the denial letter sent from the MCO.
  - Appeals must be filed within 60 days of receiving notification of the denial or other impact on services.
  - Appeals may be filed by calling the MCO Member Services or in writing.

### Requesting an Expedited Appeal

• If you or your child's provider think your child's health may be at risk if there is a delay in services, you can request an expedited appeal for it to be reviewed faster.

### **Requesting a Fair Hearing**

• You have the right to ask for a hearing with the HSD (Medicaid) Fair Hearings Bureau if, after exhausting the MCO's internal appeal process, you do not agree with the final decision, or if the MCO denied your request for an expedited appeal. Information on how to request a fair hearing is found on the denial letter sent from the MCO.

#### Filing a grievance

• A grievance is also known as a complaint. It is an expression of dissatisfaction about any matter or part of the MCO or its services. For example, if you are unhappy with a provider or the quality of a provider network.

To file a grievance, contact your MCO's Member Services department by phone or through their website:

Blue Cross Blue Shield	1-877-232-5518	www.bcbsnm.com/community-
of New Mexico	and select option 3	centennial
Presbyterian Health Plan	505-923-8858 or 505-923-5200	www.phs.org/centennialcare
Western Sky	1-844-543-8996	www.westernskycommunityc
Community Care	and press 2	are.com



### What is In-Home Support?

In-home support provides nursing or aide services for individuals based on their acuity and needs.

### Supports:

- A Private Duty Nurse (PDN) provides nursing services per the individual's nursing plan of care and the NM Nurse Practice Act.
- A Home Health Aide (HHA) provides total care or assistance with activities of daily living.

### **Determination:**

The Medically Fragile program uses a specific parameter tool to evaluate the intensity of needs an individual has. Using the tool, a level and the number of hours the individual qualifies for is determined.

### Accessing the services:

- The allotted number of hours utilized on a daily or weekly basis is determined by the individual or family.
- The RN case manager will assist with communicating needs to the nursing agency(ies), in the area, on a monthly and as needed basis.
- When an agency has an available nurse, an in-home "Meet and Greet" visit will be scheduled.
- A clinical supervisor from the nursing agency will be assigned to the individual and meet with the individual and family every 60 days for recertification. The clinical supervisor coordinates the utilization of hours, supervises PDN and HHA services and schedules.





# **RIGHTS AND RESPONSIBILITIES**

# As with any services, each individual involved in receiving and providing services has rights and responsibilities.

### The rights and responsibilities of the Medically Fragile Case Management Program are reviewed at the initial and annual Individualized Service Plan (ISP) meetings and as needed throughout the year.

### *Individuals and families being served have the right to:*

- Receive accurate information and be fully informed of services available to them
- Have their information be kept confidential and only shared on an as needed basis and with their permission
- Be treated with respect, free from abuse and discrimination, with full recognition of their dignity and individuality
- Participation in the Medically Fragile Non-Waiver EPSDT Program (MFE) is voluntary and you may choose to no longer participate at any time.
- Appeal any decision made regarding eligibility, service delivery, and termination of services.

### All individuals, family and team leaders have the responsibility to:

- Continue in their roles, for example, parents (biological, foster and adopted) remain the primary caregivers for their child. Services and supports are supplements to the individual and family's natural supports, but not replacements for the family, informal caregiver support or other community services.
- Show consideration, courtesy and respect to all persons involved with the individual's care.
- Collaborate with your child's interdisciplinary team (IDT) including being available to meet with the Nurse Case Manager for a face-to-face visit at least every other month, and by telephone on the months the face-to-face visits are not held.
- Maintain the child's Medicaid and current information with the Income Support Division (ISD).
- Make sure that the individual has a minimum of an annual appointment with their PCP.
- Notify your RN/CM of any change in status, including hospitalization of the child.



### Registered Nurse Case Manager's role and responsibilities include:

- Provide professional, courteous and confidential RN case management that is person centered and family driven in order to support the individual and family to live at home.
- Provide assessment, coordination and oversight of services and supports for individuals who are medically fragile and their families, with monitoring progress towards goals.
- Maintain regular (at least monthly) communication with the individual/family, nursing agency and MCO and as needed communication with other service providers and IDT members.
- Monthly documentation of progress towards goals, medical status and needs of individual and family.
- Be available to individual/families with prompt return of messages within one working day.
- Annually reassess eligibility for services and complete necessary paperwork on time.
- Report any known or suspected incidents of abuse, neglect and/or exploitation (ANE).
- Follow all Medicaid, Department of Health, and UNM Policies and Procedures.

To request a new copy of your rights and responsibilities contact your RN Case Manager or the main office.

For concerns regarding eligibility, service delivery, and termination of services it is best to discuss with the nurse case manager first.

If the problem remains unresolved, contact the MFCMP Program Director, Ann Marie Parmenter, at 505-362-6932.

For ongoing concerns related to eligibility determination or termination of services, contact the MCO Care Coordinator. Level of Care eligibility and Individual Service Plan (ISP) denials come from the MCO. The MCO sends the individual/family a letter describing what happened and what the appeal process is. The contact information and phone number are on the denial letter and on the individual's Medicaid card.

For Medicaid Exempt from MCO members contact the Medical Assistance Division/Exempt Services and Programs Bureau (ESPB) in Santa Fe at 505-827-7776.





# **ABUSE, NEGLECT AND EXPLOITATION**

### **Reporting Child Abuse or Neglect**

"New Mexico "Duty to Report Child Abuse and Child Neglect" law (32A-4-3) states that every person who knows, or has reasonable suspicion, that a child is being abused or neglected in New Mexico must report the matter immediately to CYFD's Statewide Central Intake (SCI) child abuse hotline (1-855-333-SAFE [7233] or #SAFE from a cell phone), law enforcement, or the appropriate tribal identity." (From <a href="https://www.cyfd.nm.gov/">https://www.cyfd.nm.gov/</a>)

Per CYFD, "When making a report of abuse or neglect, you may choose to remain anonymous as the reporter, and will be immune from liability, civil or criminal, as long as you have acted in good faith by reporting.

We encourage reporters to provide information about who they are, as it assists us in the investigative process." (From <u>https://www.cyfd.nm.gov/</u>)

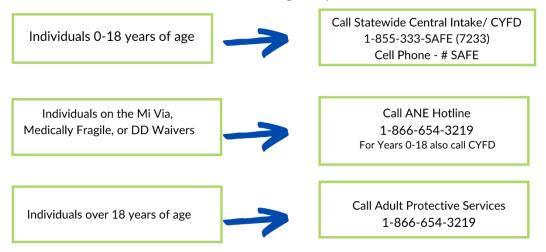
To report suspected or known child abuse or neglect:

- Dial #SAFE (7233) from a cell phone
- Call 1-855-333-SAFE (7233)
- Text 505-591-9444 (to report via text message)

Call any time, day or night - CYFD Statewide Central Intake is staffed 24/7/365.

# ABUSE NEGLECT EXPLOITATION REPORT IT!

In case of an Emergency call 911



Lines are open 24/7. When you call the numbers above, you can remain anonymous and all the information is kept confidential.



### Family Infant Toddler (FIT) Program Early Childhood Intervention Services

- For infants and toddlers, birth to age 3, and their families
- Early Intervention promotes development when a child is identified as having, or at risk for, a developmental disability or delay.
- The early intervention team will consist of services, including therapies, identified as necessary in the Individualized Family Service Plan.
- The FIT Program bills Medicaid and private insurance with the agreement of the parent. A law passed in 2005 requires that all health insurance plans cover up to \$3,500 per year in FIT services. The FIT Program does not charge copays or deductibles.
- If the child's family or doctor, child care professional, or other provider are concerned about a child's development, they can make a referral to the local Family Infant Toddler (FIT) Program.
- The local FIT Provider agency in the child's county upon receiving the referral will set up a time to meet and complete a developmental evaluation of the child.
- To find a local FIT Provider agency refer to the <u>FIT Contact List</u>.





# **SENDING YOUR CHILD TO SCHOOL**

Special education services begin as early as 3 years old. If your child has, or is suspected of having a delay or disability, it is important to contact your local school district to identify services and resources.

Sending your child who is medically fragile to school can be an exciting and fun time for both you and them. Preparing for it can be a bit scary and daunting, but there are supports available.

Here are a few tips for making the school experience successful:

- Communicate with the school early so they have time to ensure all necessary supports are in place for your child.
- Share that your child has or may need an Individualized Education Plan (IEP), Individualized Health Plan (IHP) and/or 504.
- Use this <u>Transition Worksheet [PDF]</u> to share important information with new school staff about your child.
- Start a communication journal that travels back and forth to school with your child for:
  - Staff (teacher, therapists) to help your child share what went on during their day, especially if they are non-verbal.
  - You, as the parent, to share special considerations, like your child having a rough night's sleep the night before or a change in a medication that may affect them.
- Start early in gathering necessary medical paperwork for school, such as their Seizure Action Plan and necessary rescue medication.
- Communicate with school staff about when your child's schedule may require a late arrival, early dismissal or absence.
- Remember, you are an expert in your child's needs and their biggest advocate. Share what will help your child reach their fullest potential.





### Need help with special education or the IEP process?

Contact the Office of the Special Education Ombud (OSEO)

- The Office of the Special Education Ombud provides comprehensive information, resources, and support to public school students and families navigating the special education system in New Mexico.
  - o Call the intake and information line: (505) 841-4565
  - Email the Special Education State Ombud
    - Michelle Tregembo: <u>Michelle.Tregembo@state.nm.us</u>

# DO YOU HAVE A DISABILITY OR NEED HELP WITH SPECIAL ED?

THE OFFICE OF THE SPECIAL EDUCATION OMBUD CAN HELP!



- We advocate for public school students and their families
- We provide comprehensive support for people navigating the special education system in NM



Developmental Disabilities Council



# **ACCESSING SUPPLIES**

# Durable Medical Equipment (DME) providers support access to necessary supplies and equipment.

#### Some tips in accessing necessary supplies:

- Diapers are available through Medicaid beginning at age 3 years old.
  - The child's medical provider can provide an order, with their visit notes, to the DME provider contracted with the child's MCO.
- Placing the order 5-10 business days prior to the supply anniversary date allows time for the order to be filled and shipped.
- For backordered supplies, such as formula, the child's provider will need to provide an order for an alternative.
- If a certain supply is needed above the amount that Medicaid allows, the child's medical provider can request an exception with appropriate justification and approval from the MCO.

### Accessing equipment, like a wheelchair

- 1. Identify DME providers contracted with the MCO
- 2. If accessing an equipment/wheelchair evaluation with a therapist, they can help navigate the DME provider
- 3. Wheelchairs may be authorized for an eligible recipient:
  - a. Under 21 years of age, every 36 months or 3 years
  - **b.** For adults, every 60 months or 5 years.
  - c. Earlier authorization is possible when dictated by medical necessity.

### Finding a DME provider

Contact the insurance/MCO, refer to the insurance/MCO member handbook, or view insurance/MCO website to identify contracted DME providers

#### **Recycle or reuse DME equipment**

Look for places like <u>Adelante's Back in Use</u> in Albuquerque which takes donations of equipment and recycles it to new individuals who need it. Includes equipment like, wheelchairs, walkers, and hospital beds.





### **Accessing Alternative Placement**

An alternative to home and community-based services through a waiver program, for individuals who meet the level of care requirements, is to access an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID).

An ICF/IID is a Medicaid benefit which provides a residential setting in which the individual receives the support, supervision and treatment needed to thrive.

The Human Services Department notes, "The ICF/IID benefit provides active treatment in **the least restrictive setting** and **includes all needed services** for individuals whose mental or physical condition require services on a regular basis that are above the level of a room and board setting, and can only be provided in a facility which is equipped and staffed to provide the appropriate ICF/IID services."

There are a variety of ICF/IID providers throughout New Mexico, with facilities that are individually licensed and certified by the Department of Health.

These residential setting facilities are located in the community and may include up to sixteen beds with an average of 6 beds in a facility.

For more information on ICF/IIDs and the care and services they provide, please visit - <u>https://www.hsd.state.nm.us/lookingforinformation/intermediate-care-facility-ifc-iid/</u>.

There is only one ICF/IID licensed organization in New Mexico that accepts children and young adults – Casa Angelica. Casa Angelica is a home for children and young adults with developmental disabilities, owned and operated by the Canossian Daughters of Charity since 1967. For more information about Casa Angelica, please visit <u>https://casa-angelica.com/</u>.



For emergencies - Dial 911

Suicide and Crisis Lifeline – Dial 988

Poison Control Centers - 800-222-1222

### Adaptive Equipment/Assistive Technology

- Need assistance accessing assistive technology or adaptive technology services? <u>NMTAP</u>
- <u>Carrie Tingley Hospital Foundation</u> provides assistance to children receiving care at Carrie Tingley Hospital and their families for items such as adaptive devices.
- <u>Adelante Back in Use</u> recycles durable medical equipment and assistive devices and provides them free of charge to those who need them. Call 505.341.7171 or go to their website to request equipment or make an appointment to donate.

### **Community Access / Activity**

- <u>America the Beautiful-The National Parks and Federal Recreational Lands Access Pass</u>-A free, lifetime pass - available to individuals with a disability. Provides access to more than 2,000 recreation sites.
- <u>Carrie Tingley Hospital Foundation</u> Quality Life Programming includes summer camp, virtual camp, wheelchair basketball, and Tread Setters Adaptive Cycling
- o Traillink.com Look up the best wheelchair accessible trails around New Mexico -
- <u>Adaptive Sports Program New Mexico</u> offers therapeutic recreational activities to children and adults with disabilities.

### Early Intervention Services (Birth to 3 years)

• Find an El Provider - FIT CONTACT LIST or Refer for services - FIT Referrals

### **Emergency Preparedness**

• **<u>Ready.gov</u>** provides tips on being prepared for an emergency

### Financial

- ABLE accounts allow a person with a disability to save money without losing eligibility for Medicaid, Supplemental Security Income (SSI), and other programs. Money in the account is used for qualified disability expenses. Find out more at <u>ABLE New Mexico</u>.
- A Special Needs Trust allows a person with a disability additional financial support without risk of losing important benefits. Find out more at <u>The Arc of New Mexico</u>.

Food



- Supplemental Nutrition Assistance Program (SNAP), formerly known as the Food Stamp Program
  - Apply at <u>YesNM</u>
- Need emergency food assistance?
  - Click <u>NM Food Banks</u> or <u>Roadrunner Food Bank</u> to find food banks in your area
- Do you live on an Indian reservation or are you Native American?
  - Food Distribution Program on Indian Reservations (FDPIR) provides USDA Foods to income-eligible households living on Indian reservations and to Native American households residing in designated areas.

### Guardianship

 Need assistance with navigating guardianship and alternatives to guardianship? <u>Office of</u> <u>Guardianship</u>

### Housing

- Need public housing assistance?
  - Contact your local Public Housing Agency at Choose your state or <u>NM HUD</u>.
- Need emergency housing?
  - o Emergency Shelter
- Need help with rent or utilities?
  - o St. Vincent de Paul or call 505-346-1500
  - o <u>NM Home Fund</u>
- Facing eviction?
  - o <u>NM Eviction Prevention</u>
- Own your home, but need help with mortgage and utilities?
  - o <u>St. Vincent de Paul</u> or call 505-346-1500
  - o <u>NM Home Fund</u>
- Accessing the internet
  - <u>The Affordable Connectivity Program</u> provides a discount of up to \$30 per month toward internet service for eligible households and up to \$75 per month for households on qualifying Tribal lands. Eligible households can also receive a onetime discount towards computer equipment.
- <u>Carrie Tingley Hospital Foundation</u> provides assistance to children receiving care at Carrie Tingley Hospital and their families for items such as ADA accessible home improvements, and rent and utilities.



### Medicaid MCO Contacts

- BCBS of NM Customer Service 1-866-689-1523
  - o BCBS Ombudsman 888-243-1134 <u>nmcentennialcareombudsman@bcbsnm.com</u>
- o Presbyterian 505-923-5678 or 1-800-356-2219
  - Presbyterian Ombudsman 505-923-5780 <u>ombudsman@phs.org</u>
- o Western Sky Community Care 1-844-543-8966
  - WSCC Ombudsman 844-225-6672 <u>ombudsman@westernskycommunitycare.com</u>
- Care Coordination can be requested through any of the MCOs and provides support with accessing necessary care and treatments and addressing barriers to access.

### **Mental Health**

- Suicide and Crisis Lifeline Dial 988 or 1-800-273-8255; Available 24 hours a day. The 24/7 Lifeline for Emotional, Mental or Substance Misuse Support
- o UNM Mental Health (505)272-2800
- Alcoholics Anonymous (505)266-1900
- o AGORA UNM Crisis Center (505)277-3013
- o Domestic Violence Hotline 1-800-773-3645
- National Maternal Mental Health Hotline 1-833-TLC-MAMA (1-833-852-6262)

### **Miscellaneous Information**

- Disability Questions? Contact the <u>UNM Center for Development & Disability Information</u> <u>Network</u> - 800.552.8195 or 505.272.8549.
- Informational Tip Sheets from the CDD provide information that may be helpful for persons with disabilities.
- <u>Parents Reaching Out (PRO)</u> provides support, training and tools for families and youth with disabilities or complex medical needs.
- <u>NM Disability Resource FINDER</u> is a directory of services, programs and helpful articles for the disability community.
- SHARE New Mexico is provides a searchable, comprehensive resource directory.
- o <u>NM DOH Resource Guide for Children and Youth with Special Health Care Needs</u>



### School

- Need help navigating special education and the IEP process?
  - Contact Special Education Ombud (505) 841-4565/ <u>Michelle.Tregembo@state.nm.us</u>
  - <u>Education for Parents of Indian Children with Special Needs (EPICS)</u> provides support to Native American children with disabilities and special healthcare needs.
  - NM Public Education Department Special Education <u>Resources</u>
- <u>Parents Reaching Out (PRO)</u> provides support, training and tools for families and youth with disabilities or complex medical needs navigating many aspects, including school.

### Self-Advocacy

- <u>The New Mexico Center for Self Advocacy</u> holds an Advocate Leadership Academy which provides education, resources and hands-on experience.
- <u>The Leadership Education in Neurodevelopmental and Related Disabilities (LEND)</u> traineeship provides interdisciplinary training and education to self-advocate leaders, family members of individuals with disabilities, students and professionals.

### **Transition Support**

- Healthcare transition
  - <u>Got Transition</u> aims to help youth and young adults move from pediatric to adult health care.
- Youth to adult transition
  - o School-to-Work Transition Guide
  - <u>DVR Transition Services</u> supports students with disabilities as they move from high school to the world of work & adult life.

#### Transportation

- o Door-to-door /curb-to-curb accessible transportation Search by City, State or Zip Code
- o Sun Van Paratransit service in Albuquerque
- Accessible Vehicles United Access of Albuquerque Freedom Motors

#### **Specific Health Needs**

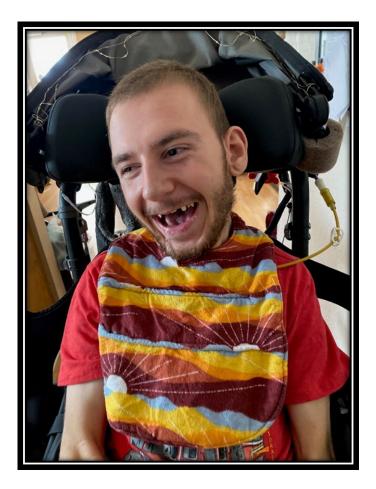
- <u>The Morgan Project</u> Provides an extensive list of disability resources and connections
- <u>National Organization for Rare Disorders</u> search their database for information and resources
- <u>Complex Child</u> is a source of information written by parents of children with healthcare needs and disabilities
- o Parenting Special Needs Magazine
- o <u>Clinicaltrials.gov</u> is a searchable site to find clinical trials from around the world
- o Dravet Syndrome Foundation



- o The Arc Provides resources from health to future planning
- o Make-A-Wish
- o Federation for Children with Special Needs
- $\circ$  Service Dogs
  - o New Horizons Service Dogs
- o Safety Beds
  - o SleepSafe Beds
- o Air Transportation
  - <u>Children's Flight of Hope</u> and <u>Miracle Flights</u> provide flights to specialized medical care

### Support groups

- o PACER Center
- o Mommies of Miracles | Facebook
- o The Global Tracheostomy Collaborative
- o Caregiver Action Network





# **APPENDICES**

#### Glossary/Acronyms

- CDD Center for Development and Disability
- DDSD Developmental Disabilities Supports Division
- DOH Department of Health
- E-Mods Environmental Modifications
- EPSDT Early and Periodic Screening, Diagnostic and Treatment
- HHA Home Health Aide
- HSD Human Services Department
- ICF Intermediate Care Facility
- IDT Interdisciplinary Team
- IEP Individualized Education Plan
- ISD Income Support Division
- ISP Individualized Service Plan
- LOC Level of Care
- LPN Licensed Practical Nurse
- MCO Managed Care Organizations (NM Medicaid Providers)
- MFCMP Medically Fragile Case Management Program
- MFE- Medically Fragile Non-Waiver EPSDT Program
- MFW Medically Fragile Waiver program
- OSEO Office of the Special Education Ombud
- PDN Private Duty Nursing
- OT Occupational Therapy
- PRO Parents Reaching Out
- PT Physical Therapy
- RN Registered Nurse
- SLP Speech Language Therapy
- SME Specialized Medical Equipment



