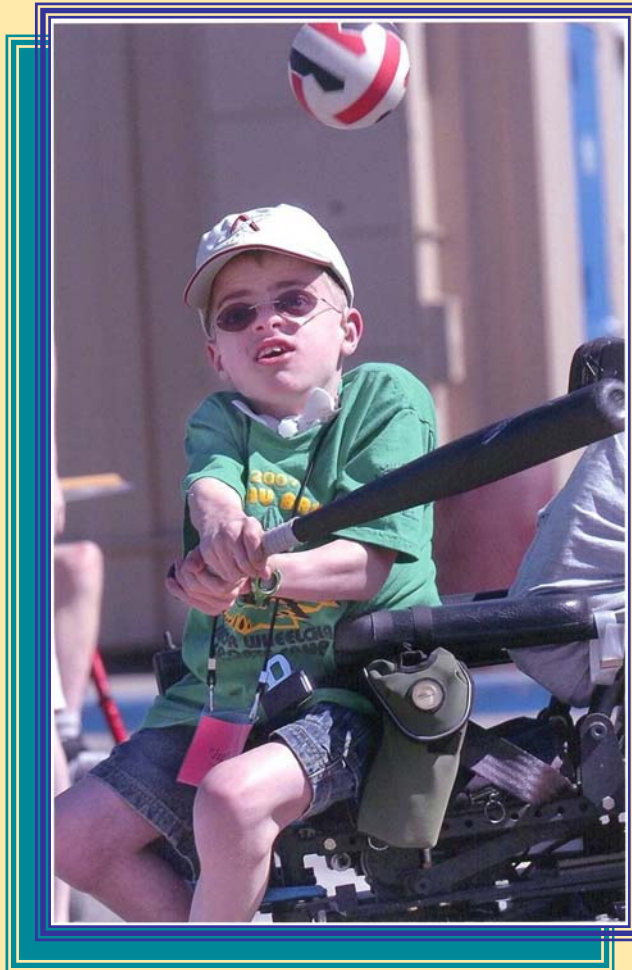


Family Handbook

Revised September
2011

Photograph by Jim Thompson, Albuquerque
Journal
Carrie Tingley Hospital Foundation



April 2008

Prepared by:

The Medically Fragile Case Management Program

Center for Development and Disability

University of New Mexico

2300 Menaul Blvd. NE

Albuquerque, NM 87107



Heaven's Very Special Child



A meeting was held quite far from earth.
It's time again for another birth,
said the angels to the heavens above.
This special child will need much love.
Her progress may seem very slow.
Accomplishments she may not show
and she will require extra care,
from folks she meets way down there.
She may not run or laugh or play:
Her thoughts may seem quite far away.
In many ways she won't adapt.
And she'll be known as handicapped.
So let's be careful where she's sent.
We want her life to be content.
Please help find parents who
will do a special job for you.
They will not realize right away
the leading role they've been asked to play
But with this child sent from above
comes stronger faith and richer love.
And soon they'll know the privilege given
in caring for this gift from heaven.
Their precious charge, meek and mild,
is Heaven's very special child.

Author Unknown

Welcome to the Medically Fragile Case Management Program

Center for Development and Disability / UNM Health Sciences Center

(505) 272-2910 or Toll Free 1-800-675-2910

Purpose of Handbook

The purpose of the parent handbook is to provide you with resources and information regarding the Medically Fragile Case Management program (MFCMP). We hope this handbook can answer questions you may have, provide information, and/or act as a resource for gathering specific information for your child's specific needs. For more information on the MFCMP, please contact your Case Manager, or call (505) 272-2910.

**by
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Family Specialist, MFCMP**

edited by
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CDD/EC&SPD

*Our dream of creating this handbook was made possible
by the support and expertise of many people.*

We appreciate the families and colleagues who have embraced this book and given wonderful, creative input. Thank you to each one of you.

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Dear Family:

This notebook has been designed and made especially for you. Either your child has been recently diagnosed with a special healthcare need or your child has been living with a chronic illness. In either case, you are not alone.

Your child has recently been diagnosed with a medical need. Your life has changed and you are going to take on a whole new role. Questions and concerns, duties and demands rage through your mind and you ask yourself...How am I going to make it through this with my child?

This book will help to prepare you for the full participation in the development of your Medically Fragile or EPSDT plan. You will find information on how to plan for your family life and your child's future. All of the things you learn from this book will help you to participate as a partner in the Individual Service Plan (ISP) process. More importantly, you will be better prepared for your most important role – *being an advocate for your child*. You and your child will meet many wonderful people along the way that will help you to grow and develop and enjoy life together. While their commitment will be limited, your parenting is a lifetime commitment.

It is up to all of us to make sure that the lives our children lead are lives of value, of quality, and dignity. It is our responsibility to be sure that the world provides meaningful opportunities, choices, and the respect our children so deserve. Your ISP is the beginning...the first step you take in building the kind of life you hope for and dream of for your child and your family.

The notebook has been divided into *two* sections. The *first* section is a **Family Handbook** designed to inform you of the processes and services provided for medically fragile and developmentally disabled children and/or adults who may qualify under certain programs.

The *second* section is the **Care Notebook** containing information sheets. Please take the time to look through each section and find those that will best help you care for your child and yourself.

Do not let this packet of papers overwhelm you! You may not need some of the information presented in this book right now. Some sections may seem very long and involved, and some of the questions may not apply to your child. You only need to fill out the parts that pertain to your child.

For the family with a child with medical needs, paperwork becomes critical in your child's care. Emergency Room visits, hospital admissions, and new physician or therapist usually have little or no background on your child. The goal of the **Care Notebook** was designed to make it easier in helping you organize and maintain

important information necessary for your family, other caregivers, and professionals. Use it as a reference book, medical documentation, or as an autobiography, as you continue through the years. We hope you will find this notebook helpful in:

- ◆ Understanding services available to your child under two different service programs – Medically Fragile Waiver and/or EPSDT through the Medically Fragile Case Management Program
- ◆ Maintaining personal and medical information
- ◆ Organizing contacts with specialists, providers, etc.
- ◆ Recording changes and details of the illness and treatments.
- ◆ Documenting changes that you would like to make, questions, concerns, etc. in regards to your child's care.
- ◆ Planning for your child's future, both financially and medically.

You have entered a new world of jargon and acronyms. A glossary and a list of acronyms have been provided on pages I-29 to I-40 to help familiarize you with many of the terms that may be used during meetings and general conversation. As time goes on, you may notice that *you too* will be using them in your daily language regarding the care of your child.

Good luck. Hope this makes your journey smoother.

If you have any questions, please contact our office.

**Medically Fragile Case
Management Program**

Main Line: (505) 272-2910

Toll Free: (800) 675-2910

Fax: (505) 272-8100

Section I



Family Handbook

CHAPTER 1

Medically Fragile Case Management Program

The Medically Fragile Case Management Program (MFCMP) is based at the Center for Development and Disability (CDD) at the UNM Health Sciences Center. It provides statewide Registered Nurse (RN) Case Management coverage with offices in Artesia, Clovis, Farmington (2), Santa Fe, and Espanola, as well as the Albuquerque area.

The MFCMP provides RN/case management services for children who are medically fragile and their families. This happens through the Medically Fragile Waiver Program through the Developmental Disabilities Support Division (DDSD) at the Department of Health (DOH); Medicaid/EPSTD (Early Periodic Screening, Diagnosis, and Treatment); and the Enhancement of Services Program through the Medical Assistance Division at the Human Services Department. The MFCMP has contracts with all four Salud! programs – Molina, Presbyterian Salud!, Lovelace Community Health Plan, Blue Salud, as well as Medicaid/Fee-for-Service (FFS). All programs provide in-home services that support you and your family in the care of your child who is medically fragile.

The primary focus is on the interaction between parents and professionals to develop and implement successful programs that provide in-home services. The goals are to address you and your child's needs within the community setting and to access resources that will assist you in stabilizing your child's health.

You and your family are the primary caregivers for health services. Your home environment is probably the greatest influence on your child's life. As a family-centered program, care goes beyond the individual's health needs to ensure that the scope of all services delivered are flexible, accessible, and responsive to your whole family unit. Your case manager works to facilitate this process.

Your Case Manager will assist you in coordinating, managing, and overseeing activities related to your child's care. Your Case Manager supports you as parents, as the team leaders, who address the day-to-day care of your medically fragile child.

A Family Resource Specialist has joined the MFCMP to provide additional assistance and support to families in their journey with their child.

There are (three) ways to receive medically fragile services:

1. Through the Medically Fragile Waiver;
2. Through a Medicaid program called EPSTD; or
3. Through Exempt Services with the DOH.

The eligibility criteria, application process, and enrollment process is as follows.

WHAT IS THE MEDICALLY FRAGILE WAIVER?

The Medically Fragile Waiver is a home and community-based waiver administered through the DDS at the Department of Health. The Medically Fragile Waiver is intended to assist individuals who have been determined to have both a medically fragile condition and a developmental disability to live in their homes with their families.

WHAT IS THE DEFINITION OF MEDICALLY FRAGILE?

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:

- ◆ There is a life threatening condition characterized by a reasonably frequent period of acute exacerbation, which requires frequent medical supervision, and/or physician consultation, and which in the absence of such supervision or consultation, would require hospitalization.
- ◆ The individual requires frequent time-consuming administration of specialized treatments, which are medically necessary.
- ◆ The individual is dependent on medical technology such that without the technology, a reasonable level of health could not be maintained. Examples include, but are not limited to, ventilators, dialysis machines, enteral or parenteral nutrition support, and continuous oxygen.

ELIGIBILITY:

The individual applying for the Medically Fragile Waiver must meet both the medical and financial eligibility criteria set forth by Medicaid.

- ◆ The individual must be diagnosed by the age of 22 years with the condition that makes you medically fragile.
- ◆ The individual must be living at home.
- ◆ The individual must also meet the Level of Care (LOC) criteria.
- ◆ After the initial assessment and determination for eligibility, the individual will be reassessed annually to determine medical fragility and developmental disability.
- ◆ Services will continue through the individual's lifespan as long as the medically fragile and developmental disability criteria are met.

FINANCIAL:

In order to be considered financially eligible, the individual must meet the income guidelines specific to Category 95/Medically Fragile Waiver (MFW), by the Medicaid Income Support Division (ISD). The Medically Fragile Waiver Program does not claim the income and resources of the representative (parent, legal guardian), only the child's income and resources.

MEDICAL:

The LOC eligibility is approved or denied by the New Mexico Medicaid Utilization Review (NMMUR) agency that is contracted with Human Services Department (HSD) Medical Assistance Division (MAD).

If the applicant is not financially eligible for Medicaid, the applicant will receive Medicaid as a result of an approved LOC and Individualized Service Plan (ISP) for the Medically Fragile Waiver. Medicaid eligibility is effective the day that the ISP is approved. However, the individual is not entered into the Medicaid system until 30 days after the ISP is approved. The Medicaid start is retroactive back to the initial ISP date.

(More follows on the development of an ISP on page I-8)

WHAT IS THE DEFINITION OF A DEVELOPMENTAL DISABILITY?

- ◆ Begins before the age of 22
- ◆ Continues indefinitely
- ◆ Results in functional limitation in three or more of the following areas:
 - ◇ Self-Care
 - ◇ Language
 - ◇ Learning
 - ◇ Mobility
 - ◇ Self-Direction
 - ◇ Independent Living
 - ◇ Economic Self-Sufficiency
- ◆ Results from mental and/or physical impairment
- ◆ Reflects a need for individualized special support services for an extended period of time

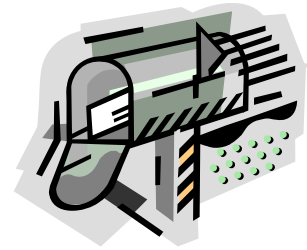
WHAT SERVICE OPTIONS ARE OFFERED THROUGH THE MEDICALLY FRAGILE WAIVER PROGRAM?

- ◆ Case Management (is required)
- ◆ Private Duty Nursing (RN & LPN)
- ◆ Home Health Aide
- ◆ Physical Therapy
- ◆ Speech Therapy
- ◆ Occupational Therapy
- ◆ Behavior Therapy Support
- ◆ Psychosocial Counseling for Recipient and/or Family Members
- ◆ Nutritional Counseling
- ◆ Respite (In-home Respite)

*If the individual is under the age of 22, services will be provided by:
Early Periodic Screening, Diagnosis, and Treatment (EPSDT).
More to follow on services through EDSDT.*

Please see the Income Support Division phone numbers listed by County for the State of New Mexico on page I-45.

YOU HAVE BEEN ALLOCATED FOR THE MEDICALLY FRAGILE WAIVER



GATHERING INFORMATION FOR YOUR CHILD'S LEVEL OF CARE (LOC)

- ◆ The Income Support Division (ISD) office will be contacting the applicant and/or family to complete required paperwork for the Medically Fragile Waiver, while the Case Manager (CM) is meeting with you and gathering the information for the Level of Care (LOC).
- ◆ The applicant or the applicant's representative will be responsible for completing the *Application/Redetermination of Eligibility for Medical Assistance (MAD 381)* form and returning it to the County ISD. **If not contacted within ten (10) days from the date of the letter** to schedule an appointment, it will be **your** responsibility to contact the office. This step is important and goes on at the same time as the LOC determination.
- ◆ A CM will be calling to set up an in-home, face-to-face visit with your child and family in order to start the process that will include determining your child's LOC. The LOC is the compilation of information that describes the medical care needs that the applicant has. The information is scored so that an acuity level is documented.

To determine the LOC, the applicant's CM will meet with them and their family to gather information regarding the applicant's overall health, medical diagnosis, developmental disability, issues, and concerns. The CM will also discuss the individual's daily living skills and any concerns or support that is needed. The CM will also collect information on the individual's current support system. This helps demonstrate that the necessary criterion has been met to receive services.

- ◆ Your CM and Primary Care Physician (PCP) share the responsibility of completing the required paperwork for the *Level of Care*.
- ◆ The CM will review the specific Medically Fragile Waiver criteria used to determine the applicant's skilled care needs and their daily living skills.
- ◆ An Interdisciplinary Team meeting (IDT) will be scheduled for your child to develop the ISP. The team will consist of the applicant, the applicant's family, guardians, CM, and direct service providers (such as an Occupational Therapist (OT) Speech-Language Pathologist (SLP) or a Physical Therapist (PT), and the PCP. The plan defines the services the applicant will receive,

including the cost of services and a schedule for when and where the services will be delivered. The CM will talk with you about the team meeting and whom the applicant and their family would like to participate in the meeting. Input regarding the applicant's strengths and needs are important in the development of a personal vision for a broad service plan. All therapists and developmental specialists will develop goals and approaches for the upcoming year to meet those needs. The IDT must review the treatment plan at least every twelve months or more often if needed.

WHAT IS AN INDIVIDUALIZED SERVICE PLAN (ISP)?

The ISP is an individualized and person centered plan, based on your child's needs, dreams, wishes, and desired outcomes, which includes services and supports necessary for the achievement of your family's stated desires.

It is important to remember to ask questions about anything you don't understand. These planning meetings can be very overwhelming in the beginning. Have your CM explain anything you don't understand.

An ISP will address medical and psychological needs. Any medical information, medications, equipment, and behavior plans will be included.

A blank copy of an ISP report will follow to help familiarize yourself to the plan process.

The blank ISP form that follows on Pg. I-8 has been provided to familiarize you with the development of an ISP. Remember, your input will be valued during this process. This is a time to plan for your child.

WHAT IS THE ROLE OF YOUR CASE MANAGER (CM) DURING THIS PROCESS?

- ◆ Supports the individual's and family's decision to care for the individual within the home.
- ◆ Advocates for the individual and the family.
- ◆ Identifies priorities and concerns for the individual and family.
- ◆ Increases the individual's and the family's understanding of the service delivery system and processes, and acts as a companion to help navigate the system.

*What is an advocate?
One that supports or promotes and helps in voicing the interests of another.*

- ◆ Mentors the individual to enhance your abilities to *direct your own* services.
- ◆ In collaboration with the individual and the family, facilitates the team planning process and ensures the right people are involved.
- ◆ Identifies the individual's needs and sets up the IDT.
- ◆ Reviews progress and chosen outcomes, goals and objectives *with the individual and the family* and revises the ISP as needed.
- ◆ Monitors your satisfaction regarding services delivered according to the ISP.
- ◆ Serves as a liaison between the IDT. This includes the healthcare team, community providers, Family Infant Toddler (FIT) program, and public school systems.
- ◆ Locates and coordinates community services and resources according to the needs of the individual and the family.
- ◆ Maintains records and makes sure that data has been recorded and analyzed in order to give good reason for eligibility; makes necessary changes to the services and the ISP in accordance with state and federal program guidelines.

If you live in a rural area, there may be limited services or no services available at all. Talk to your CM about what services are available where you live. Remember: It is not just about getting services. It should be about making a better life for the individual. Plan to use services and therapies to support yourself or your child as a member of the community. Always try to think creatively.

**UNM HEALTH SCIENCES CENTER
CENTER FOR DEVELOPMENT AND DISABILITY**
Medically Fragile Case Management Program
2300 Menaul Blvd. NE
Albuquerque, New Mexico 87107
(505) 272-2910 or (800) 675-2910

INDIVIDUALIZED SERVICE PLAN

Name: _____

Program: Medically Fragile Waiver _____ or EPSDT _____

Initial: _____ **Reassessment:** _____

ISP Cycle Dates: _____

Six-Month Review Completed By: Date: _____

Check one:

Initial _____

Early Intervention _____

Optional _____

Primary Diagnosis/ICD 9 Code (*Add Mixed Developmental Disorder/315.5 if EI Recipient*)

Date of Birth/Age: _____ **Adjusted Age:** _____

Address: _____

Telephone Number: _____

MFCMP ID NO.: _____

Insurance Coverage: _____

Salud! Provider: _____

Family Members: _____

Primary Language: _____

TEAM MEMBERS:

Name / Duration / Frequency / Funding

PRENATAL HISTORY:

HEALTH HISTORY / CURRENT STATUS:

MEDICAL FRAGILITY ASSESSMENT FACTORS

A. MEDICATION ADMINISTRATION:

B. MEDICAL CARE and SUPERVISION:

C. NUTRITION and FEEDING:

HEIGHT:

WEIGHT:

BMI:

D. RESPIRATORY:

E. NEUROLOGICAL:

F. OTHER COMPLEX MEDICAL/SKILLED CARE TREATMENTS

G. MEDICAL IMPACT BASED ON ABILITY FOR SELF CARE

H. FAMILY SUPPORT ISSUES

I. SLEEP PATTERN:

J. ALLERGIES:

K. IMMUNIZATIONS:

L. VISION:

M. DENTAL:

DEVELOPMENTAL TESTING

CURRENT LEVEL OF FUNCTIONING

A. SENSORIMOTOR DEVELOPMENT

- a. Mobility: _____
- b. Toileting: _____
- c. Hygiene: _____
- d. Dressing: _____

B. INDEPENDENT LIVING SKILLS

- a. Home Skills: _____
- b. Community Skills: _____

C. SPEECH AND LANGUAGE DEVELOPMENT

- a. Expressive: _____
- b. Receptive: _____

D. COGNITIVE DEVELOPMENT: _____

E. AUDITORY FUNCTIONING: _____

F. VISION: _____

G. DENTAL: _____

H. BEHAVIORAL ISSUES (formerly Maladaptive Behaviors):

I. NATURAL ENVIRONMENT: _____

**This ISP serves as a guideline for care. It does not constitute a physician's orders.
This ISP will vary as the client's needs change.**

FAMILY

(Recipient's name) has participated in the development of his/her Individualized Service Plan.

OR

(Recipient's name) is not able to participate in the development of his/her Individualized Service Plan due to.

Case Manager has discussed with the (recipient and/or family) that they have the option of receiving psychosocial counseling. The (recipient and/or family) has/have chosen to

(Recipient's Name) Strengths and Needs:

Recipient/Family Strengths:

Recipient/Family Concerns, Priorities and Outcomes:

Issues (Includes recipient/family, medical, developmental)

Goals and Objectives (developed by all Interdisciplinary Team Members):

Care Activity/Strategies: All items relate to (a) recipient's/family's priorities and outcomes; and (b) interdisciplinary team (IDT) goals and objectives.

Medical:

Nursing:

HHA:

Respite – In-home or Institutional:

Occupational Therapy (home-based/center-based):

Physical Therapy (home-based/center-based):

Speech-Language Therapy (home-based/center-based):

Psychosocial Counseling:

Nutritional Counseling:

Specialized Medical Equipment (SME):

Medical Supply Company:

School:

Case Management: The Case Manager (CM) will coordinate *(Recipient's name)* services through the Medically Fragile Case Management Program including nursing, therapeutic services, durable medical equipment and supplies, and other needs as identified by the family, healthcare team, and delineated in the ISP and IEP *(IEP added only if the child has one)*. The CM will make bimonthly, face-to-face home visits and communicate by telephone on the months the home visits aren't held. The CM will be available by telephone on an as-needed basis, and reevaluate the plan on an ongoing basis, making adjustments as necessary, and coordinate a formal reevaluation in six months with the entire team if indicated. The client's eligibility and this ISP will be reassessed annually.

EQUIPMENT & SUPPLIES

Article	Source	Funding

MEDICATIONS

Name	Dosage	Frequency	Route



The University of New Mexico ♥ Health Sciences Center
SCHOOL OF MEDICINE

Center for Development and Disability
Department of Pediatrics
Medically Fragile Case Management Program
2300 Menaul NE
Albuquerque, NM 87107
Telephone (505) 272-2910
Toll Free: 1-800-675-2910
Fax (505) 272-8100

RIGHTS AND RESPONSIBILITIES

As a recipient/family receiving services through the Medically Fragile Case Management Program (MFCMP), you have certain rights and responsibilities. Please refer to the Family Handbook provided to you for more detailed information.

SECTION 1: RECIPIENT/FAMILY RIGHTS

All Recipients and Families Have the Right to:

1. Be fully informed of services available to them, and their required participation in the development of the Individualized Service Plan (ISP).
2. Choose providers and case management agencies when alternative providers are available. Once services have begun, service providers may be changed, if needed.
3. Confidentiality: Your written consent is required for the release of medical, psychological or therapeutic information to persons not involved in your care.
4. Be free from mental or physical abuse and discrimination based on race, color, creed, gender, age, disability or sexual orientation.
5. Be treated with consideration, respect and full recognition of his/her dignity and individuality, including privacy in treatment and in care for his/her personal needs.
6. Accurate information. Participation in the Medically Fragile Waiver is voluntary. However, according to State regulations you are required to receive home health and case management services. Failure to comply may jeopardize your slot on the Medically Fragile Waiver.
7. Appeal any decision made regarding eligibility, service delivery, and termination of services.

SECTION 2: RECIPIENT/FAMILY GRIEVANCE INFORMATION. (Process to address denials as described in Section 1 - #7)

1. Concerns regarding eligibility, service delivery, and termination of services should be addressed first with your case manager.
2. Response to any appeal/grievances with Medicaid/Salud or the Medically Fragile Waiver shall occur within five-(5) working days. All matters are treated confidentially.
3. For **EPSDT Medicaid/Salud Program** recipients receiving services through the MFCMP: Contact your SALUD! Program for their specific appeal/grievance process through the toll free member services number. Your case manager has that number.
4. For Medicaid recipients that are classified as **EXEMPT from SALUD**, the appeal/grievance is submitted to the Program Manager at the Medical Assistance Division/Benefits Bureau in Santa Fe. (505) 827-3113
5. If you do not feel the problem has been resolved, contact the MFCMP Program Director at (505)-272-2910 or 1-800-675-2910. The Program Director has information on the appeal/grievance process if needed.
6. For the **Medically Fragile Waiver** recipients; if you still feel that the problem has not been resolved, contact the Medically Fragile Waiver Manager at Developmental Disabilities Supports Division/Department of Health at (505) 841-2913.

SECTION 3: INDIVIDUAL/FAMILY/TEAM LEADER RESPONSIBILITIES:

1. Services and supports are not replacements for the family, informal caregiver support or other community services, but are supplements to the recipient's natural supports. The parents (biological, foster and adopted) are the primary caregivers for their child.
2. Show consideration, courtesy and respect to all persons involved with the recipient's care and to facilitate the same consideration from family/friends in your home. To ensure that all behave in such a manner that providers are not threatened, abused or injured.
3. Collaborate with your case manager, physician, and provider agencies in the implementation of the ISP.
4. Provide necessary information to the Income Support Division (ISD) office. Notify the Income Support Division (ISD) office of any change of status, such as address, name or income changes. Foster Families will follow agency guidelines. Families who have adopted through CYFD will follow agency guidelines.
5. Be available to meet with case manager at a face-to-face visit at least every other month, and by telephone on the months the face-to-face visits aren't held, or to notify case manager if unable to do so.

6. Notify your case manager regarding any of the following:
 - Hospitalization
 - Changes in
 - income (which may affect your EPSDT Medicaid benefit)
 - address, telephone number
 - change in primary caregivers
 - Changes of physicians, therapists, medical suppliers
 - Name changes in case of adoption
 - Periods of time in which scheduled services will need to be changed, or for a request for respite
 - Any services being received from another in-home agency

SECTION 4: RN/CASE MANAGER'S ROLE and RESPONSIBILITIES:

1. Assist and support recipients who are medically fragile and their families by linking individuals and their families to natural supports and direct service providers.
2. Identify and assist in accessing the supports and services needed for the recipient to live at home.
3. Assist the recipient/family in the development of the ISP based on the needs identified by the recipient/family and the Interdisciplinary Team (IDT). The IDT consists of physicians, service providers, FIT programs and schools.
4. Assist the recipient/family in coordinating services through the MFCMP including home health services, therapies, durable medical equipment and supplies as well as other needs identified by the recipient/family and the IDT.
5. Monitor the delivery of these services as specified in the individual's ISP.
6. Maintain regular communication with the recipient/family and the service providers and the IDT.
7. Make a minimum of every other month face-to-face visit.
8. Be available to recipients/families, returning messages within one working day.
9. Re-evaluate the ISP on an ongoing basis, making revisions as necessary.
10. Coordinate a formal re-evaluation in 6 months for FIT clients, or when needed or requested.
11. Annually reassess eligibility for services and complete necessary paperwork.
12. Report any known or suspected incidents of abuse, neglect and/or exploitation.
13. Follow all Medicaid, Department of Health, and UNM Policies and Procedures.

I have read and understand both my rights and responsibilities as a recipient/family member of the MFCMP, CDD, UNM HSC. I have also read the MFCMP RN/Case manager's role and responsibilities.

Signature of Recipient

Date

Signature of Parent/Guardian

Relationship to Recipient

Date

Signature of Case Manager

Date

CHAPTER 2

What is the Early Periodic Screening, Diagnosis and Treatment (EPSDT)?

EPSDT is the *Medicaid* healthcare benefit package for individuals who are ages birth to 21 years old. Children must meet the financial guidelines for Medicaid eligibility.

THESE SERVICES MAY INCLUDE:

- ◆ Preventive Check-ups
- ◆ Diagnostic Tests
- ◆ Speech Therapy
- ◆ Occupational Therapy
- ◆ Physical Therapy
- ◆ Behavior Therapy
- ◆ Private Duty Nursing
- ◆ Home Health Aide

Please Note
To receive EPSDT services, your child does not have to have a developmental disability as on the MFW. Eligibility is based on medical fragility and Medicaid financial criteria.

TO RECEIVE SERVICES UNDER EPSDT:

- ◆ EPSDT services must be ordered by a physician or primary care provider (PCP) and be medically necessary.
- ◆ You must also meet eligibility criteria for medical fragility.
- ◆ You must be on Medicaid and/or receiving Social Security Supplemental Income (SSI). The family's income is taken into account.
- ◆ Benefits would end on the individuals 21st birthday, or if the family/individual's income changes.

This program provides case management and in-home private duty nursing (RN/LPN) and Home Health Aide (HHA) services. The child's Medicaid card purchases other services such as therapies.

Reassessment of eligibility is done every 12 months. Six-month reviews are done for all children served through the FIT Program, as well as for individuals who are on their initial Individual Service Plan (ISP) cycle.

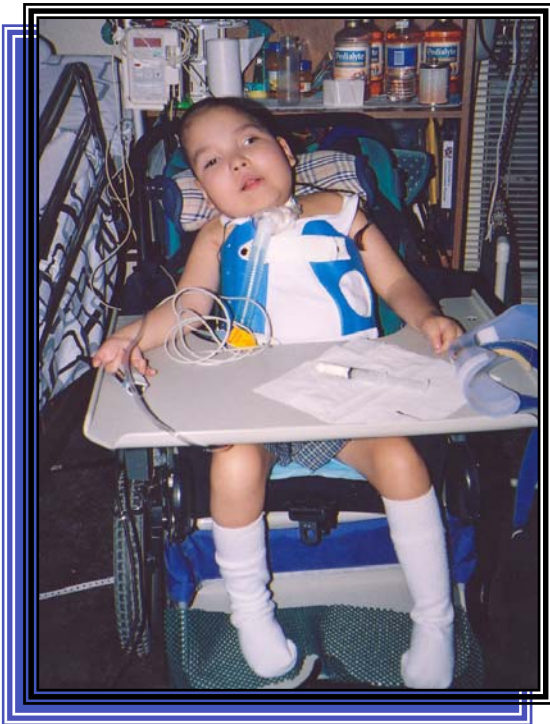
EPSDT services are administered through the four Saluds! – Molina, Presbyterian, Lovelace, and Blue Salud or Fee for Service (FFS) Medicaid.

Please note: for children under age 21 who are on a waiver program, all home healthcare services (therapies, private duty nursing, personal care services, and home health aids) are provided by EPSDT. These services are not paid through the waiver programs.

Respite services are available through the waiver programs but **not** through EPSDT. Sometimes it is difficult to distinguish between Respite and Personal Care, which **is** covered by EPSDT/Medicaid. Respite is for the primary purpose of relieving the child's caregiver and is therefore not covered by EPSDT. Personal Care is covered because it is focused on the child's needs and is not intended to relieve the primary caregiver. Personal Care **is** provided for children through EPSDT, but must be prescribed as medically necessary by a doctor or PCP.

Remember
It is vital for respite "time away" for family members acting as caregivers.

The Income Support Division (ISD) provides services to New Mexicans out of the central office in Santa Fe, as well as through 33 offices statewide. The ISD assists families in need of food, temporary financial assistance, and healthcare services through Medicaid. The application process for waiver services may begin at the ISD office.



WHAT IS THE ROLE OF NURSING AGENCIES AND VARIOUS OTHER AGENCIES?

While your child is on the Medically Fragile Case Management Program (MFCMP), services offered through Home Health Care are intended to provide the best quality of life for your child, as well as give some assistance to *you*, the *family*, in caring for *your child*.

Remember
"It isn't easy allowing strangers into your home to care for your special child, but it is vital that there is some balance in the situation."

WHAT SERVICES MIGHT BE AVAILABLE FOR MY CHILD THROUGH HOME HEALTHCARE?

Services Available:

- ◆ Assessment
- ◆ Enteral/Parenteral Therapies
- ◆ Medication Instruction
- ◆ Bathing and Other Personal Care
- ◆ Teaching Ostomy Care
- ◆ Education on Disease Management
- ◆ Venipuncture (surgical puncture of a vein especially for the withdrawal of blood or for administration of intravenous fluids or drugs)
- ◆ Nutrition Counseling
- ◆ Catheter Care/Changes
- ◆ Infusion Therapies
- ◆ Monitoring of Acute Conditions
- ◆ Therapies: PT, OT, ST
- ◆ Wound Care/Dressing Changes
- ◆ Ostomy Management (an operation, like a colostomy, ileostomy, or urostomy) to create an artificial passage for bodily elimination)

SERVICES NOT ALLOWED:

- ◆ The nurse or HHA is only assigned to your child who is on the program; not to any siblings or other children under 18 years of age who reside in the house.
- ◆ The siblings cannot be left alone in the house with the nurse or HHA.
- ◆ No intermittent care; meaning a nurse would come to your home just to do an assessment or to come on an as-needed basis. A schedule will be arranged in accordance to the Level of Care (LOC) for services.

The home health agency will let you know what the HHA's job description includes. An example might be transporting of your child by the nurse or HHA is determined by the agency that employs them.

CHAPTER 3

What Early Childhood Services are Available?

WHAT IS THE FAMILY INFANT TODDLER PROGRAM (FIT)?

The Family Infant Toddler Program (FIT) is located within the Department of Health (DOH). If your child is age birth to three years old, and you have concerns about your child's development or situations that might affect their development, then the FIT Program is there for you. This may lead to a recommendation made by yourself or other professionals involved with your child's life, with your permission, to a local Early Intervention program. Either the local Children's Medical Services (CMS) Family Infant Toddler (FIT) worker or the local Early Intervention program will receive the referral. In New Mexico, the Department of Health (DOH) is the lead agency to provide and organize services and support to children who have or who are at risk of developmental delay.

WHAT IS EARLY INTERVENTION (EI)?

Early Intervention supports a child's learning and development during the important time from birth to three years of age. The early intervention program is staffed with professionals to provide ideas on how to best help meet your child's development and health-related needs.

A service coordinator will meet with your family to explain about Early Intervention, including your rights, and help plan your child's evaluation.

You and Early Intervention professionals will work as a team to develop a plan called the Individualized Family Service Plan (IFSP). You as a parent, will work with the members of the team to decide:

- ◆ What changes/outcomes you would like to see for your child's services provided through Early Intervention;
- ◆ What will need to happen to help make these changes occur; and
- ◆ What kinds of services will be provided to help you and other people in your child's life to make the identified changes happen.

Remember

Opportunities exist during the course of the day to incorporate into your child's routine to help enhance the child's learning experiences. The team can help with ideas and suggestions to support intervention strategies.

CHAPTER 4

What is Social Security Supplemental Income (SSI), and How Do I Apply

The Social Security Supplemental Income (SSI) is a cash assistance program for a person with a disability based on medical need and income eligibility, which includes Medicaid benefits. Children with severe physical or mental impairments, premature infants, and low birth weights are eligible for SSI.

This program provides monthly income checks to children and adults who qualify under the **Social Security Administration's** definition of disability and family income limits. If your child is determined eligible, the parent or guardian will receive a check on behalf of your child. If your child is under the age of 18, your income will be considered as part of the income eligibility. At age 18, they are then considered an adult. They must requalify using the rules that apply to adults with disabilities. Only their income will then be considered.

For children to be defined as having a disability, the SSA (the federal agency in charge of SSI) reviews how his or her disability affects everyday life. The child must meet the following criteria:

- ◆ Have a proven physical or mental condition which results in “marked and severe functional limitations”
- ◆ The condition must last at least 12 months or be expected to result in death
- ◆ The child must not be working at a job that the SSA considers to be substantial work

The child's condition must be reviewed occasionally by SSA to determine if it is still disabling, and evidence must be provided that the child is being treated for his or her condition.

RESOURCES **Social Security Administration**

To apply for benefits or for more information, you can call (800) 772-1213.

*If you know your child will **not** qualify due to income, call the 800 number to request a phone interview.*

*The Social Security Administration has many informational materials available which can be requested such as: **Supplemental Security Income; Benefits for Children with Disabilities; and Working While Disabled.***

CHAPTER 4

Other Waiver Programs Available in New Mexico

Family Tips

As you begin receiving medically fragile services, please keep in mind there are other waiver services offered within our state.

As we look towards the future, our hopes would be that your child may not need the intensity of medical services they are currently receiving and would possibly benefit from services through other waivers.

There may be a long period of time before your child comes up for an allocation slot for many of the other waivers. It is advised that you apply for them early. When your child's name comes up for an allocation, if the services provided by that particular waiver wouldn't serve your child well, you can always refuse services at the time or request a hold status. It is better to be safe than sorry.

A description of other waivers available to individuals with disabilities follows. Your Case Manager or your Family Specialist can also assist you with more details or other questions you may have.

THE DEVELOPMENTAL DISABILITIES (DD) HOME AND COMMUNITY-BASED WAIVER

The **DD Waiver** is a home and community-based alternative to institutionalization in an intermediate care facility for the mentally retarded (ICF-MR). The program serves individuals who are diagnosed with a developmental disability prior to age 21 and who meet the same level of care criteria required for institutional care. They must meet Medicaid eligibility criteria for income and resources.

SERVICE OPTIONS OFFERED THROUGH THE DEVELOPMENTAL DISABILITIES WAIVER PROGRAM

- ◆ Case Management
- ◆ Therapies: Speech-Language, Physical, and Occupational
- ◆ Respite
- ◆ Private Duty Nursing for Adults
- ◆ Non-Medical Transportation
- ◆ Nutritional Counseling

Other services may be available through the Mi Via Self-Directed option of the DD Waiver. Contact Consumer Direct Personal Care for an information packet:

(866) 786-4999

- ◆ Goods and Services
- ◆ Behavioral Support
- ◆ Community Living Supports
- ◆ Community Inclusion
- ◆ Environmental Modification
- ◆ Supplemental Dental Care
- ◆ Personal Plan Facilitation

COORDINATION OF LONG TERM SERVICES (COLTS): *formerly known as THE DISABLED AND ELDERLY (D&E) WAIVER PROGRAM*

CoLTS is a home and community-based waiver designed to provide assistance to the disabled and elderly, (adults and children) requiring long term care so they can remain in their home. CoLTS manages health care and long term services for certain Medicaid recipients. They are managed by two managed care organizations (MCO's), Evercare and Amerigroup. This program is an alternative to a nursing facility.

- ◆ To qualify, a person must be 65 years of age or older or have a disability (blind or disabled), who reside in the community, and for which an application for home and community-based services has been registered with Aging and Long-Term Services. However, a person may still be eligible for services if they qualify for medically disabled, but not as elderly.
- ◆ The applicant must meet **both** financial and medical eligibility requirements as determined by Medicaid.
 - ◇ For medical eligibility, a person is considered disabled if they require assistance with at least two activities of daily living and meet a Nursing Facility level of care due to medical disability which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.
 - ◇ Financial eligibility considers both income and resources.

SERVICE OPTIONS OFFERED THROUGH COLTS WAIVER

- ◆ Case Management
- ◆ Adult Day Health
- ◆ Assisted Living

Contact Aging and Long-Term Services Division (ALTSD) Resource Center at (800)-432-2080 for more information.

- ◆ Emergency Response Services
- ◆ Environmental Modification
- ◆ Homemaker Services for Adults
- ◆ Occupational, Physical, and Speech Therapy for Adults
- ◆ Private Duty Nursing for Adults
- ◆ Respite Services

MI VIA - SELF-DIRECTED WAIVER SERVICES

Individuals who are currently receiving services under a traditional waiver have the choice to participate in *Mi Via*, a self-directed program. They will have more choices, control, and freedom to design their own service plans to meet their functional, medical, and social needs.

The **Mi Via Self-Directed Waiver** participants create their own plan, choose the services they need, hire their own service workers, and decide where and how to spend their *Mi Via* budget. A consultant is available to provide assistance as necessary.

For more information about Mi Via Self-Directed Waiver, contact Consumer Direct Personal Care at (866)786-4999. Ask for an information packet to be sent to you.

Waiver recipients who receive services through waiver programs, such as the CoLTS, Developmental Disabilities (DD), Medically Fragile (MF), AIDS, and individuals with brain injuries are eligible for *Mi Via*.

The Brain Injury Service Fund is not technically a “waiver.” It provides and supports individuals who are age 18 and older, with a traumatic brain injury (TBI). To qualify for service, you or your loved one must have a physician diagnosis, verified in writing of a TBI. For more information, call the Brain Injury Association at (888) 292-7415.

THE AIDS WAIVER

The Aids Waiver helps New Mexicans with AIDS to live in their homes. To qualify for services, you or your loved one must have a diagnosis of AIDS. For more information, call (505) 476-3628.

CHAPTER 5 Resources

Glossary

Access: Ability to receive timely services from a healthcare system, insurance plan or provider.

Activities of Daily Living (ADL): Your required activities to get through the day, such as dressing, and bathing.

Acute Care: Medical services provided after an accident or illness, usually for a short time.

Allocation: As money becomes available, persons who are awaiting services on the Central Registry are offered an opportunity to receive services. This chance to receive services is called an “allocation.” Allocations from the Central Registry are made by registration date. There is an eligibility process that follows.

Ambulatory Care: Medical services provided outside of a hospital.

Assessment: A collection of information from a variety of sources that includes doctor, nurse, school, Early Intervention program, etc. that looks at the strengths and challenges of a person. Once allocated to a waiver or designated to receive EPSDT services, professionals will do an assessment or evaluation of the needs, strengths, and challenges of the person, with regard to their particular area of expertise.

Annual Reassessment: Every year the previous ISP will be revised and updated, using information from the ISP meeting.

Adult Protective Services—Investigates allegations of abuse and/or neglect of adults—individuals over 18 years of age.

Benefit: Medical services guaranteed to be covered by the healthcare plan. Examples are: treatment of illness or injury, and medically necessary supplies or equipment.

Case Manager: A person employed by the Medically Fragile Waiver, the Saluds!, or Fee-for-Service (FFS) Medicaid who is knowledgeable about the various health services available and how to access them. Case Managers are responsible for helping children who are medically fragile and their families learn about services available to them and how to access those services for which they are eligible. They help assess your child’s and your abilities to coordinate the team who serve your child and you through your ISP, monitor services, health and safety issues, and access resources in your community. The Case Manager brings your child’s interdisciplinary team together.

Child Protective Services: Investigates allegations of abuse, neglect, and exploitation of children.

Children’s Medical Services (CMS): A state and federally-funded program, which is part of the New Mexico Department of Health. It provides services to children with special needs, including medical management, outreach clinics (cleft palate, pulmonary, dysmorphology, neurology, endocrinology), newborn genetic screening, and hearing screening, etc.

Co-Payment: What a member pays for each health visit or service received. Co-pay prices vary, but they are often between \$5.00 and \$40.00 for prescriptions and office visits.

Deductible: The amount the member agrees to pay for health services before the health insurance pays.

Department of Health (DOH): State Agency that oversees the Developmental Disability Waiver (DD Waiver) and the Medically Fragile Waiver through the Developmental Disabilities Support Division—DDSD.

Developmental Disability Waiver (DDW): Allows persons with limitations to access supports and resources through Medicaid and the Waiver so they can live as independently as possible if they are financially and medically eligible for the Waiver.

Developmental Screening (Developmental Checkup): A short, simple examination or test that is used to find out if a child is developing as most children do. It usually includes a check of the child’s hearing, vision, growth, physical skills, communication skills, thinking skills, and social-emotional skills. Both New Mexico Family Infant Toddler Program (Early Intervention) and the Medicaid EPSDT program include developmental screening as a service for all eligible children.

Durable Medical Equipment (DME): Necessary medical equipment that is not disposable. Examples are: wheel chairs, walkers, ventilators, and commodes, etc.

Early Intervention Program: A state and federally-funded program, which in New Mexico is managed by the Department of Health and is called the New Mexico Family Infant Toddler Program (FIT). It is a program that provides intervention services for families with children ages birth to 3 years, who are at-risk for or have delays in development or disabilities. Services are provided in accordance with state regulations and the federal Individuals with Disabilities Education Act (IDEA) regulations. Services include developmental screening and evaluation, service coordination, and intervention.

Eligibility: In order for an individual to receive services through a Medicaid Waiver Program, they must meet the eligibility criteria. When you apply, the DOH/DDSD will screen the information to be sure the person meets the requirements. After you receive

notice that there is an open “funding slot,” or allocation, you will be asked to provide documentation showing that the individual requires a certain level of care (medical eligibility), and the individual meets the financial requirements (financial eligibility).

Enrollee: Usually referred to as a member of the health insurance plan who receives benefits from that plan.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT): A federal program mandated by Medicaid since the 1960s. The EPSDT program serves children birth to 21 years who are enrolled in the state’s Medicaid program. It is a program designed to identify and treat children with health or developmental concerns. The child must be financially eligible for Medicaid.

Exempt: You are excused from being part of a program that other people are required to be part of. For example, if you are Medicaid Exempt in New Mexico, you can receive Medicaid services, but you do not have to join one of the Medicaid Salud! managed care organizations. Exempt means “exempt from Salud!” Fee-for-Service (FFS) is another name.

Fee-for-Service (FFS): A traditional health insurance plan that allows the member to choose the providers and services, often with a deductible and co-payment. The system of payment allows the individual provider to bill the funding source directly. For example, in New Mexico Medicaid Exempt members can choose their own Medicaid approved providers without a referral. Those approved Medicaid providers do not have to go through the Medicaid managed care system to get paid.

Formulary: A list of prescription medications, which the health insurance plan agrees to pay for. Prescription medications, which are not on this list, are usually not paid for by the health plan.

Grievance Procedure: Action steps that individuals receiving services through Medicaid/FFS, Medically Fragile Waiver, the Salud! programs or health insurance plan members, or providers can take when there is a disagreement about the plan’s services, billings, or general procedures.

Health Maintenance Organization (HMO): A type of managed healthcare insurance plan that provides services through a network of doctors, hospitals, laboratories and pharmacies. This is the same as a Managed Care Organization (MCO). Each member is required to choose a primary care provider that manages the member’s healthcare and makes referrals when appropriate. There is no deductible or claims to file, but the member usually has to pay a co-pay at the time service is provided. Usually referral is needed for services outside the primary care provider’s office and prior authorization is needed for some services.

High Risk Insurance Pool: A state program that allows people who cannot get healthcare coverage because of a pre-existing health condition to join together to purchase membership in a healthcare plan. Usually premium rates are high.

Health Insurance Portability And Accountability Act (HIPAA): The Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA, Title II) required the Department of Health and Human Services (HHS) to establish national standards for electronic healthcare transactions and national identifiers for providers, health plans, and employers. It also addressed the security and privacy of health data. HIPAA has confidentiality rules.

Home Health Aide (HHA): A trained and certified healthcare worker who may also be called a CNA—certified nursing assistant. The HHA is CPR certified and must meet other specific certification guidelines. The HHA provides assistance to a patient in the home with vital signs, feeding, personal care (such as hygiene and exercise), follow-up with therapy exercise, range of motion, etc., and light household duties (as meal preparation), and also monitors the patient's condition. The HHA works with the family in the care of their child. Many times the HHA cannot be left alone with the child who is medically fragile. The HHA cannot do any treatments, give medications, or do medical assessments, etc.

Income Support Division (ISD) or Human Services Division (HSD): A division of the New Mexico Human Services Department. Your local Income Support Division office is one of the places you can go to apply for Medicaid or other public assistance programs. Phone numbers for local offices are listed in the blue pages of the phone book, under State Government, Income Support Division.

Individualized Education Plan (IEP): An Individual Education Plan that is developed for school age children by an IEP team which consists of parents, the student, teacher, therapists, and administrators.

Individual Family Service Plan (IFSP): An individualized plan designed for your child and family to focus on changes (referred to as *outcomes*) that you want to see for your child as a result of your participation in Early Intervention. After your child is transitioned to the public schools, the IFSP is changed to an IEP.

Individualized Service Plan (ISP): An Individualized Service Plan is what the IDT team develops at the annual meeting. It will include the person's vision, goals, and budget for the coming year. Another name may be a Plan of Care.

Indemnity Health Plans: A health plan that allows you to choose any provider that accepts that health plan. After paying a deductible, the health plan pays for some portion of the services. These plans typically require the member to pay for the service and then submit a claim for reimbursement. The member is not required to have a primary care provider and referrals are not usually required. Some services require prior authorization.

Indian Health Service (IHS): A program that is part of the United States Public Health Service (PHS), and provides health and medical services to American Indian and Alaskan Native people.

Interdisciplinary Team (IDT): Your team that includes a Case Manager, therapists, guardian, other providers, and persons you choose. This team meets at least twice a year to develop and make changes to your individual service plan.

Income Support Division: A division under the Human Services Department (HSD). This division will process your initial registration form, along with any information regarding financial eligibility. Many ISD forms are called MAD with a number after it.

Level of Care (LOC): To determine the LOC, your Case Manager will meet with you to gather information regarding your family member's overall health, developmental disability, and the impact of his/her daily living skills, along with information on the current support system. This helps demonstrate that the necessary criteria have been met to receive services.

Limitation: Services not paid for or limited in some way by the healthcare plan. Examples are: acupuncture is usually not paid for; or therapy services may be limited to a certain number of visits.

Licensed Practical Nurse (LPN): A nurse who has completed a one- or two-year training program in healthcare and earned a state license. LPN's provide direct patient care for people with chronic illness, in nursing homes, hospitals, and home settings. They practice under the supervision of a registered nurse (RN).

Medicaid: A program of medical aid designed for those unable to afford regular medical service and financed jointly by the State and Federal Governments. Eligibility and services vary from state to state. Eligibility groups include low-income families with children as described by Section 1931 of the Social Security Act. All states cover a minimum group of services including hospital, physician, and nursing home services. States have the option to include coverage for 31 other services, including prescription medications, and hospice care.

Medicaid SCHIP: A federal and state health insurance program run by states. It was created as part of the Federal Balanced Budget Act of 1997. It expands Medicaid coverage to children whose families earn too much for Medicaid, but too little to pay for private health insurance.

Medical Assistance Division (MAD): The Medical Assistance Division is a division under the Human Services Department. The MAD is the division that administers the Medicaid insurance benefit.

Medically Fragile Waiver Program (MFWP): A home and community-based Medicaid waiver authorized under Section 1915C of the Social Security Act that was originally

approved in New Mexico in 1985. The program is designed to serve individuals who are medically fragile through their lifespan as long as they meet medical and developmental eligibility requirements. They must have their medically fragile diagnosis prior to the age of 22 years old.

Medicare: A federal health insurance program for people who are 65 years or older, people who are disabled, and people with permanent kidney failure. Medicare has two parts. Part A covers inpatient hospital services, skilled nursing facilities, home health services and hospice care. Part B covers physician services, medical equipment and supplies, and other health services and supplies.

Medicaid Waivers: The State of New Mexico, Human Services Department, Medical Assistance Division (HSD/MAD) obtained a waiver from the United States Department of Health and Human Services, Centers for Medicare and Medicaid Services to provide Home and Community-Based Services (HCBS) programs to individuals that require long-term supports and services. This was done so individuals who qualify may remain in their family residence, in their own home, or in community residences. The programs serve as alternatives to institutional care. New Mexico has five HCBS waiver programs: Acquired Immunodeficiency Syndrome (AIDS); Developmentally Disabled (DD); Disabled and Elderly (D&E); Medically Fragile (MF); and Mi Via, a self-directed waiver.

Medical Necessity: A legal term used to determine eligibility for a health benefit and service. It describes services that are consistent with a diagnosis and meets standards of medical practice for the illness or injury.

Member Handbook: A booklet given to health insurance plan members when they first join and thereafter annually when their membership is renewed. This book describes the services available to the health plan member, rights, and complaint and grievance procedures. It may also contain a list of the healthcare providers who contract with the health plan to provide the different services.

Mi Via: Which means “my way,” or “my road,” in Spanish, is the state’s new Medicaid self-directed waiver program, that provides a choice of goods and services to participants. Participants have a key role and responsibility in developing a flexible service and support plan that meets their needs.

Monthly Face-to-Face Visit: Monthly visit that the Case Manager makes with the family and/or individual. This visit is a requirement of the Medically Fragile Waiver and the Medicaid/Salud! programs. At the visit, the Case Manager reviews how the family/individual is doing, how services are going, any issues or concerns, and any changes that need to be made to the ISP.

Natural Environment: Settings that are natural or typical for the child’s age peers, who have no disabilities and include the home, child care, and other community settings.

Natural Supports: The people and organizations from the community that persons without disabilities might have for support, e.g., friends, family, neighbors, church organizations, club members, etc.

New MexiKids: Another name for the New Mexico Medicaid program for children.

Nutritionist: A specialist who studies how an individual takes in and utilizes food substances. A nutritionist makes a nutrition plan for the patient to assure that they are receiving adequate calories and nutrients.

Preferred Provider Organization (PPO): A private health insurance plan that uses a “network” of providers. The member can choose their providers, but typically the health plan pays a greater portion of the cost if the member uses the “network provider” instead of providers who are not in the network. Usually there is a deductible and then the health plan pays for some portion of the services. Usually, the member does not have to file a claim if the “network providers” are used, but members do have to file a claim for reimbursement if an out-of-network provider is used.

Primary Care Provider (PCP): A health professional who is responsible for coordination of all medical care, including prevention and referrals. It is usually a physician (doctor), nurse practitioner, or physician’s assistant.

Prior Authorization: Required approval by a health plan administrator before the service can be provided. This is in addition to the referral by the Primary Care Provider. Usually, if the service is approved, it will have limitations such as a limited period of time and number of visits.

Private Duty Nurse (PDN): A nurse who works in the family’s home, caring for a child who is medically fragile. Private duty nurses are RNs or LPNs. They usually do shift care at home.

Private Health Insurance Plan: An employer-sponsored group health plan or health plan purchased by an individual through professional associations, social groups, or civic groups. These plans are usually health maintenance organization (managed care) plans, preferred provider organization plans or traditional indemnity plans.

Provider: An agency or person who provides services to individuals receiving waiver services and other programs. Along with the family they help to develop goals and work towards those ISP goals.

Receipt Form: A simple form you fill out at the ISD when you turn copies and documents into the ISD office. The receptionist will give you a copy of the receipt form. Your dated copy will serve as a receipt that you turned in paperwork on a certain date. This is important when you need to get a document to them by a specified date. These

forms can usually be found at the front desk. They are called by different names, including “Change Form” and “Receipt for Proof.” Keep for your records.

Registration: This is the first step in applying for a waiver. You can do this through your local ISD office or call it into the DDSD office in the region you live in. The name of the form is the Waiver Registration Form (MAD 325 at the bottom). Complete this form and turn it into the ISD office. There is an eligibility process that follows after the MAD 325 form is registered at the ISD office or at DDSD.

Registration Date: When you turn in the Waiver Registration Form to the ISD office, you will ask them to stamp all copies with the current date, including your receipt copy of the date that you call in the information to DDSD. This is the registration date.

Referral: A written authorization from a Primary Care Provider to see a medical provider who is not part of the Primary Care Provider’s staff. An example would be a referral to an audiologist for a hearing evaluation. For some services, a health plan might require prior authorization in addition to a referral from the Primary Care Provider.

Registered Nurse (RN): A nurse who has completed a two- to four-year degree program in nursing, and provides direct patient care for acutely or chronically ill patients. RNs may further specialize in a particular area.

Respite: A service, which provides the family with a break from the care of an individual with a disability or chronic illness. Usually, a qualified respite caregiver takes care of the individual to the family’s home, the caregiver’s home, or sometimes at a special respite home. If the individual needs skilled care, a licensed nurse must provide the respite. The Medically Fragile Waiver has some in-home respite provider home health agencies.

Salud!: The name of the New Mexico Medicaid managed care program.

Six Month Review: A six-month meeting with the patient, family, Case Managers, and care providers where the plan for the patient is reviewed to see if any changes need to be made due to progress or changes in the patient’s coordination. Six-month reviews are required for individuals new to the Medically Fragile Waiver or to Medicaid/Salud! services. The six-month review is done six months after the start of the ISP. Families or the IDT can also request six-month reviews.

Supplemental Security Income (SSI): A federal program that provides monthly cash assistance to people, including children, who have low income, and who meet certain age or disability requirements. Enrollment in SSI also includes access to Medicaid.

Temporary Assistance for Needy Families (TANF): A federal and state program for low-income families, providing them with financial assistance and job training.

TRICARE: A regionally managed public healthcare program for active duty and retired members of the uniformed armed services (military), their families, and survivors. Health plan options include TRICARE Prime (managed healthcare primarily at military facilities), TRICARE Extra (a preferred provider option), and TRICARE standard (a fee-for-service option).

Welcome to the World of Acronyms

The summary below is provided to assist you in understanding some of the most common acronyms. We hope you find this tool useful as you navigate through the various terms used in the field of disability.

AAC	Augmentative and Alternative Communication
AAMR	American Association on Mental Retardation
ABI	Acquired Brain Injury
ABS	Adaptive Behavior Scale
ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
AG	State Attorney General's Office
AL	Assisted Living
AIMS	Abnormal Involuntary Movements Screening
APE	Adapted Physical Education
APS	Adult Protective Services or Albuquerque Public Schools
ARA	Annual Resource Allotment
ARCA	Association for Retarded Citizens of Albuquerque
Arc of NM	State Advocacy Agency—Association of Retarded Citizens
ASA	Autism Society of America
ASL	American Sign Language
AT	Assistive Technology
BBS	Bureau of Blind Services
BC/BS	Blue Cross/Blue Shield
BD	Behavior Disorder
BIA	Bureau of Indian Affairs
BID	Twice a Day
BIP	Behavior Intervention Plan
BMS	Behavior Management Specialist
BSP	Behavior Support Plan
BT	Behavior Therapy or Therapist
CARF	Commission on the Accreditation of Rehabilitation Facilities
CDD	Center for Development & Disability
CEC	Council for Exceptional Children
CF	Cystic Fibrosis
CM	Case Manager
CMA	Certified Medication Aide or Case Management Assessment
CMS	Children's Medical Services or Center for Medicare and Medicaid Services (formerly HCFA: Healthcare Financing Authority)
COC	Continuum of Care Program
CP	Cerebral Palsy

CPR	Cardiopulmonary Resuscitation
CPS	Children's Protective Services
CYFD	Children, Youth and Families Department
DD	Developmental Disability
D and E	Disabled and Elderly Waiver
DDPC	Developmental Disabilities Planning Council
DDSD/DOH	Developmental Disabilities Support Division, Department of Health
DDW	Developmental Disability Waiver
DH	Day Habilitation
DHH	Deaf and Hard of Hearing
DME	Durable Medical Equipment
DOE	Department of Education
DOH	NM Department of Health
DRP	Dispute Resolution Process
DSS	Direct Support Staff
Dx	Diagnosis
DVR	Division of Vocational Rehabilitation, Department of Education
EA	Education Assistant
ECG/EKG	Electrocardiogram
ED	Emotional Disturbance
EI	Early Intervention
EEG	Electroencephalogram
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
ESL	English Second Language
ESY	Extended School Year
FAPE	Free and Appropriate Education
FERPA	Family Educational Rights and Privacy Act
FAS	Fetal Alcohol Syndrome
FBA	Functional Behavior Assessment
FCR	Family-Centered Review
FFS	Fee-for-Service
FIT	Family Infant Toddler Program
FOC	Freedom of Choice
FSA	Functional Supports Assessment
FTF	Face-to-Face
FYI	Family Youth Inc., or For Your Information
GERD	Gastro-Esophageal Reflux Disorder
GTT/GERD	Gastrostomy Tube/Gastro-Esophageal Reflux Disorder
GTT	Gastrostomy Tube
HI	Hearing Impaired
HIPAA	Health Insurance Portability & Accountability Act
HMO	Health Maintenance Organization
HSD	Human Services Department

HUD	Department of Housing and Urban Development
ICAP	Inventory for Client and Agency Planning
ICC	Interagency Coordinating Council (Early Intervention Services)
ICF	Intermediate Care Facility
ICP	Indian Children's Program
IDEA	Individuals with Disabilities Education Act
IDT	Interdisciplinary Team
IEE	Individual Education Evaluation
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
IHP	Individualized Health Plan
IQ	Intelligence Quotient
IR	Incident Report
I&R	Information and Referral
ISD	Income Support Division of the NM Human Services Department
ISP	Individualized Service Plan (for Waiver Services)
ITP	Individualized Transition Plan
LD	Learning Disability
LEP	Limited English Proficient
LINC	Library and Information Network for the Community
LPN	Licensed Practical Nurse
LOC	Level of Care
LRE	Least Restrictive Environment
MAD	Medical Assistance Division of the Human Services Department
MANDT	Positive Support Intervention System
MAR	Medication Administration Record
MAW	Medical Assistance Worker
MCO	Managed Care Organization
MD	Multiple Disabilities or Muscular Dystrophy or Medical Doctor
MFCMP	Medically Fragile Case Management Program
MFW	Medically Fragile Waiver
MR	Mental Retardation
MTP	Mealtime Plan
NC	Nutritional Counseling
NERO	Mental Health
NMMUR	New Mexico Medicaid Utilization Review
NPO	Nothing by Mouth
OCD	Obsessive Compulsive Disorder
OCR	Office of Civil Rights
OHI	Other Health Impaired
OT	Occupational Therapy
P&A	Protection and Advocacy
PBDC	Parents for Behaviorally Different Children

PC	Personal Care
PCO	Personal Care Option — for individuals over the age of 21 years who are Medicaid eligible
PCP	Primary Care Physician
PCS	Personal Care Services (approximately 3 years to 21 years through Medicaid/Saluds! — after 21 years, it is called PCO)
PDD	Pervasive Development Disorder
PDN	Private Duty Nurse—RN or LPN
PED	Public Education Department
PLP	Present Levels of Performance
PO	By Mouth
PRN	As Needed
PRO	Parents Reaching Out
PSD	Personal and Social Development
PT	Physical Therapy
RN	Registered Nurse
RO	Regional Office
ROM	Range of Motion
RX	Prescription
QA	Quality Assurance
QD	Every Day
QID	Four Times a Day
SCHIP	State Children’s Health Insurance Program
SE	Supported Employment
SGF	State General Fund
SI	Sensory Integration Treatments
SID	Sensory Integration Disorder
SIB	Self-Injurious Behavior
SL	Supported Living
SLD	Specific Learning Disability
SLT/SLP	Speech-Language Therapy/Speech-Language Pathologist
SS	Social Security
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Social Security Income
ST	Speech Therapy or Therapist
TA	Technical Assistance
TBI	Traumatic Brain Injury
TDD	Telecommunication Devices for the Deaf
TID	Three Times a Day
UH	University Hospital
UNM	University of New Mexico
UNMH	University of New Mexico Hospital

UR	Utilization Review
URI	Upper Respiratory Infection
VI	Visual Impairment
VR	Vocational Rehabilitation
VOC	Vocational
WAIS-R	Wechsler Adult Intelligence Scale

Support Groups / Community Resources

- ◆ **AIDS Helpline:** New Mexico AIDS services. Call (505) 938-7100 or (888) 882-2437.
- ◆ **Angel Flight West:** Free, non-emergency air transportation in private aircraft donated by volunteer pilots to people with healthcare and other compelling human needs; call (310) 390-2958 or (888) 426-2643; <http://www.angelflight.org>
- ◆ **Arc of New Mexico:** The Arc advocates for the reduction in the number of families struggling to support their family members and to guarantee that all persons with developmental disabilities and their families are served appropriately; located at 3655 Carlisle NE, Albuquerque, NM 87110; call (505) 883-4630 or (800) 358-6493; <http://www.arcnm.com>
- ◆ **Autism:** Programs at the Center for Development and Disability; call (505) 272-1852 or (800) 270-1861. Located at 2300 Menaul Blvd. NE, Albuquerque, NM 87107; email: autismprograms@salud.unm.edu; <http://cdd.unm.edu/autism>; *New Mexico Autism Society*, P.O. Box 30955, Albuquerque, NM 87190; call (505) 332-0306 for anyone concerned with autism; monthly meeting at 7pm third Thursday; for more meeting information, call (505) 332-0306
- ◆ **Birth Defect Research for Children, Inc. (BDRC):** The association maintains the National Birth Defect Registry, which is used to match families of children who have the same or similar birth defects; located at 930 Woodcock Road, Suite 225 Orlando, FL 32803; email: abcd@birthdefects.org; <http://www.birthdefects.org>
- ◆ **Brain Injury Association of New Mexico (BIANM):** Support for survivors of brain injury, their families and friends, professionals, educators, etc.; located at Resource Center, 121 Cardenas NE, Albuquerque, NM 87108; call (888) 292-7415. <http://www.Braininjurynm.org>; email: info@braininjurynm.org (coordination for Mi Via Waiver for acquired brain injuries)
- ◆ **Brain Injury Support Group:** Forum for brain injury survivors and their families to exchange methods for dealing with problems associated with brain injury; meets at

7pm, third Wednesday, Health South Rehabilitation Hospital, 7000 Jefferson Blvd.; NE, Albuquerque, NM 87109; call (505) 344-9478

- ◆ **Brain Injury Survivors Support Group:** Meets 7pm, first Friday, St. Joseph Rehabilitation Center, 505 Elm NE, Albuquerque, NM 87102; call (505) 727-4700 or (505) 292-7414
- ◆ **Caregiver Support Groups:** For someone who is caring for a loved one who is terminally ill, suffers from dementia, or has a chronic debilitating illness; located at First United Methodist Church, 314 Lead SW, Albuquerque, NM 87102; call (505) 243-5646. Meets Wednesday's from 6:00-6:45pm
- ◆ **Cerebral Palsy Parents Association:** Meets 6-8pm, first Thursday; located at Carrie Tingley Children's Hospital, 1127 University NE, Albuquerque, NM 87102; dinner, childcare; call (505) 272-5296 or (505) 951-1855
- ◆ **Down Syndrome Networking Group:** Parents of Special Children; contact Monica Chlastawa at (505) 892-6363; email: chlastawa@msn.com or Nadine Maes (Spanish speaking) at (505) 892-2551; email: nmaes@salud.unm.edu
- ◆ **Epilepsy Parent and Family Network of New Mexico:** Meets at 7pm, second Monday; located at St. Joseph Rehabilitation Hospital, Piñon Room, 505 Elm NE, Albuquerque, NM, 87102; call (505) 897-4656
- ◆ **Epilepsy Support Group:** Meets from 6-8pm, last Tuesday; located at University Hospital, Khatali Room, 2211 Lomas NE, Albuquerque, NM 87106; call (505) 872-2615, (505) 968-1476 (pager), or e-mail: epilepsy6@netscape.net
- ◆ **Families of Children With Disabilities:** For families who live in Torrance County; call Christie at (505) 384-1365
- ◆ **Families as Partners:** Advocacy group of parents who work with staff and administration at UNM hospitals to promote quality and family-centered care services that honor and respond to the diversity of all children and their families; contact the Child Life Program, UNM Children's Life Program, UNM Children's Hospital. Call (505) 272-2671

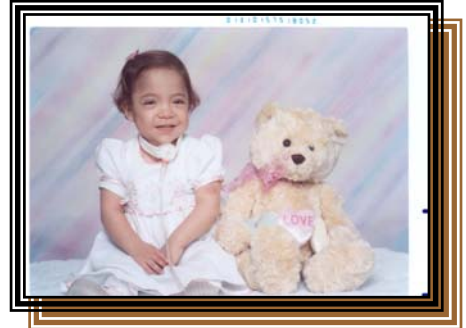
- ◆ **Huntington's Disease Support Group:** Call (505) 888-4120
- ◆ **Information Center for New Mexicans With Disabilities/BabyNet:** Located at the Center for Development and Disability; provides information to Spanish- and English-speaking New Mexicans with disabilities, families, advocates, therapists, and case managers about service providers, support groups, and other local, state, and national resources; call (800) 552-8195 or locally at (505) 272-8549; email: infonet@unm.edu
- ◆ **LINC (Library and Information Network for the Community):** Located at the Center for Development and Disability; offers comprehensive collection of disability resources; services include *Online Catalog*, 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; located at 2300 Menaul Blvd, NE, Albuquerque, NM 87107; call (800) 827-6380 or (505) 272-0281; email: linc@salud.unm.edu
- ◆ **MPS Society:** Write to: P.O. Box 736, Bangor, ME 04402; call (207) 947-1445; fax: (207) 990-3074; <http://www.mpsociety.org/>
- ◆ **MUMS National Parent-to-Parent Support Network:** This organization has a database of over 14,000 families from 45 countries covering over 2500 rare disorders. Families whose children have the same or similar disorder can find support and information by exchanging valuable information about their children. Located at 150 Custer Court, Green Bay, WI 54301-1243; call (877) 336-5333 (parents only) or (920) 336-5333; email: mums@netnet.net; www.netnet.net/mums
- ◆ **Myasthenia Gravis:** Call (505) 897-0932
- ◆ **New Mexico Kids – Early Care, Education and Family Support:** Here you can find information that supports childcare professionals, parents, and health educators in New Mexico; the website goal is to support parents and early care and educational professionals to network and access information, technical assistance, and resources; call (800) 691-9067; www.newmexicokids.org

- ◆ **Parents for Behaviorally Different Children (PBDC):** For families with behavioral, emotional challenges, including ADD, depression, and other neurobiological illnesses; for information, call (505) 265-0430 or (800) 273-7232
- ◆ **Protection and Advocacy:** Advocates working together with people who have disabilities and their families in promoting and protecting their legal and service rights; located at 1720 Louisiana Blvd. NE Suite 204, Albuquerque, NM 87110; call (505) 256-3100 or (800)432-4682; email: nmpanda@nmprotection-advocacy.com; <http://www.nmprotection-advocacy.com>
- ◆ **Organ Transplant Awareness Program of New Mexico:** Call (505) 828-0694
- ◆ **Parents Reaching Out (PRO):** For families with children (birth to age 21) with unique needs, offering support, encouragement information, resources, and workshops; call (505) 247-0192 or (800) 524-5176; email: info@parentsreachingout.org; <http://www.parentsreachingout.org>; PRO also offers a Parent to Parent Support Network
- ◆ **Sensory Processing Disorder - Parent Connection Group:** Support group for parents of children with sensory processing/sensory integration (SI) disorder. Meets from 6:30-8:00pm, first Thursday at Kid Power Therapy Association, PC, 3530 Pan American Freeway NE, Albuquerque, NM 87107; contact Darbi at (505) 247-8645
- ◆ **Spina Bifida Association of New Mexico:** Offers educational programs and information about this disabling birth defect; call (505) 242-1184 or (800) 750-2044; spinal Cord Injury Support Group meets at 5:30pm, first Thursday at St. Joseph Rehabilitation Hospital, Piñon Room, 505 Elm NE, Albuquerque, NM 87102; email: sjhscipc@hotmail.com; call (505) 244-4700, the Tuberous Sclerosis Alliance (TSA); call (800) 225-6872 or (301) 563-9890; [http:// www.ntsaa.org/](http://www.ntsaa.org/)
- ◆ **United Way Helpline:** Information and referrals to health and human services agencies; located at 2340 Alamo Ave. SE, Albuquerque, NM 87106; call (505) 245-1735; information and Resource phone (211)

New Mexico Income Support Division Offices by County

County	Address	City	Phone
Bernalillo - Northeast part of Albuquerque	4330 Cutler NE	Albuquerque, NM 87125	222-9200
Bernalillo - Northwest part of Albuquerque	1041 Lamberton NE	Albuquerque, NM 87125	841-7700
Bernalillo - Southeast part of Albuquerque	1711 Randolph Rd. SE	Albuquerque, NM 87102	383-2600
Bernalillo - Southwest part of Albuquerque	3280 Bridge Blvd. SW	Albuquerque, NM 87121	841-2300
Catron	1014 N. California St.	Socorro, NM 87801	835-0343
Chaves	1701 S. Sunset	Roswell, NM 88203	625-3000
Cibola	900 Mount Taylor Ave.	Grants, NM 87020	287-8836
Colfax	1233Whittier St.	Raton, NM 87740	445-2308
Curry	3316 North Main St. Suite A	Clovis, NM 88101	762-4751
De Baca	200 Lake Drive	Santa Rosa, NM 88435	472-3459
Dona Ana (Las Cruces/East Side Area)	2121 Summit Court	Las Cruces, NM 88011	524-6568
Dona Ana (Las Cruces/West Side Area)	655 Utah	Las Cruces, NM 88001	524-6500
Dona Ana (South Dona Ana /Anthony Area)	220 Crossett Lane	Anthony, NM 88021	882-5781
Eddy	108 N. 16th	Artesia, NM 88210	748-3361
Eddy (Carlsbad Area)	3604 San Jose Blvd.	Carlsbad, NM 88220	885-8815
Grant	3088 32 nd St. ByPass Rd. Suite A	Silver City, NM 88061	538-2948
Guadalupe	620 Historic Route 66	Santa Rosa, NM 88435	472-3459
Harding/Mora/San Miguel	2636 Ridge Runner Rd.	Las Vegas, NM 87701	456-0037
Hidalgo	109 Poplar St.	Lordsburg, NM 88045	542-3562
Lea (Hobbs area)	2120 N. Alto, Suite D	Hobbs, NM 88240	397-3400
Lincoln	26387 Hwy 70	Ruidoso, NM 88346	378-1762
Luna	910 E. Pear	Deming, NM 88030	546-0467
McKinley	3006 East Hwy. 70	Gallup, NM 87301	726-7600
Otero	2000 Juniper	Alamogordo, NM 88310	437-9260
Quay	421 W. Tucumcari Blvd.	Tucumcari, NM 88401	461-4627
Rio Arriba (Espanola area)	228 Onate Street	Espanola, NM 87532	753-2271
Rio Arriba (Tierra Amarilla area)	17345 Chama Highway	Tierra Amarilla, NM 87575	588-7103
Roosevelt	1028 Community Way	Portales, NM 88130	356-4473
Sandoval (Rio Rancho, Bernallilo area)	4363 Jagar Dr.	Rio Rancho, NM 87144	383-6300
San Juan	101 W. Animas	Farmington, NM 87499	566-9600
San Miguel	3113 Hot Springs Blvd.	Las Vegas, NM 87701	425-6741
Santa Fe (State Office)	2009 S. Pacheco	Santa Fe, NM 87504	827-7250
Santa Fe County/SF area	37 Plaza La Prensa	Santa Fe, NM 87504	476-9200
Sierra	102 Barton Street	T or C, NM 87901	894-3011
Socorro	1014 N. California St.	Socorro, NM 87801	835-0342
Taos	145 Roy Rd.	Taos, NM 87571	758-8804
Torrance	109 Tulane Ave.	Moriarty, NM 87035	832-5026
Union (Clayton area)	834 Main Street	Clayton, NM 88415	374-9401
Valencia	100 N. 5th Street 2 nd floor	Belen, NM 87002	864-5200
Valencia	445 Camino Del Ray, Suite B	Los Lunas, NM 87031	222-0800

Section II



Care Notebook

Family



We all come from families.
Families are big, small, extended, nuclear,
multi-generational, with one parent,
two parents, and grandparents.
We live under one roof or many.
A family can be as temporary as a few weeks,
as permanent as forever.
We become part of a family by birth, adoption,
marriage, or from a desire for mutual support.
As family members, we nurture, protect,
and influence one another.
Families are dynamic and are cultures unto themselves,
with different values and unique ways of realizing dreams.
Together, our families become the source of our
rich cultural heritage and spiritual diversity.
Each family has strengths and qualities that flow from
individual members and from the family as a unit, our families
create neighborhoods, communities, states, and nations.

*Developed and Adopted by New Mexico's House Memorial 5 Task 3 Force
on Children and Families and the Coalition for Children, 1990*

Emergency Information Form for Children with Special Needs

American College of Emergency Physicians
American Academy of Pediatrics

Date Form Was Completed: _____ Revised: _____ Initials: _____

Completed By: _____ Revised: _____ Initials: _____

Please Print Clearly

Name: _____ Birthdate: _____ Nickname: _____

Home Address _____ Home/Work Phone: _____

Parent/Guardian: _____

Signature/Consent: _____

Emergency Contact Names & Relationship: _____

Contact Phone Number: _____ Primary Language: _____

Physician(s):

Primary Care Physician: _____

Emergency Phone: _____ Fax: _____

Current Specialty Physician: _____

Emergency Phone: _____ Fax: _____

Current Specialty Physician: _____

Emergency Phone: _____ Fax: _____

Anticipated Primary Emergency Department: _____

Pharmacy: _____

Anticipated Tertiary Care Center: _____

*Compiled From Medical Home Website (<http://www.medicalhomeinfo.org/>)
and Revised by MFCMP/UNM Health Sciences Center, October, 2007.*

My Child's Profile - Medical Record

Personal Information

My Child's Name: _____ Nickname: _____

Date of Birth: _____ Last 4 Digits Social Security #: _____

Primary Language in Our Home: _____ Date Form Completed: _____

Primary Place of Residence: _____

City: _____ State: _____ Zip Code: _____

Family / Care Providers Emergency Contacts:

Name/Relationship	Home #	Work #	Cell #	Pager #

Primary Care Provider (Pediatrician's name, address, phone, other numbers):

Child's Name: _____

Primary and Secondary Diagnosis:

Medical Alerts: _____

Insurance Information:

Name, Last 4 Digits Social Security #, and Employer of Insured:

Address of Insured if Different From Child's:

Primary Health Insurance Company:

Billing/Correspondence Address: _____

Policy Number: _____

Phone Number _____

Secondary Health Insurance / Company

Billing/Correspondence Address: _____

Policy Number: _____

Phone Number: _____

Child's Name: _____

SURGERIES OR PROCEDURES

Type of Surgery / Procedure	Surgeon / Physician / Hospital	Date(s)

HOSPITAL ADMISSIONS (for reasons other than surgery)

Reason for Admission	Hospital	Date(s)

Child's Name: _____

RESPIRATORY CARE

Oxygen: _____ Liters Route _____ Start Date _____

SVN: Medication _____ Amount _____ Frequency _____

Suctioning: Route _____ Catheter size _____ Frequency _____

Tracheotomy: Size/Brand _____ Change Frequency _____

Ventilator: Type _____ Settings: IMV _____ SIMV _____ Volume _____

Peak Pressure _____ PEEP _____ Rate _____

Pulse Ox: Type _____ Settings: Low Alarm _____ High Alarm _____

Apnea Monitor: Type _____ Settings: High Heart Rate _____ Low Heart Rate _____

Apnea setting in seconds _____

Type _____ Settings: Pressure _____

CURRENT STATUS OF SENSORY AND ABILITY INFORMATION VISION

Last Date Tested: _____ By Whom: _____ Where: _____

Results if Known: _____

Glasses Contact Lens Prosthesis Other _____

HEARING

Last Date Tested: _____ By Whom: _____ Where: _____

Test Type/Results: _____

Test Type/Results: _____

Wears Aids Right Ear Left Ear Both Ears

Child's Name: _____

MOBILITY / ORTHOTICS

Braces: Type _____ Orthotic _____ Provided by _____

Wheel Chair: Type _____ Orthotic _____ Provided by _____

Walker: Type _____ Orthotic _____ Provided by _____

Jacket: Type _____ Orthotic _____ Provided by _____

COMMUNICATION

- | | |
|--|---|
| <input type="checkbox"/> Computer | <input type="checkbox"/> Lip-Reads |
| <input type="checkbox"/> Communication Board | <input type="checkbox"/> Interpreter Services |
| <input type="checkbox"/> Sign Language (ASL) | <input type="checkbox"/> Communication Book |
| <input type="checkbox"/> Sign Language (English) | <input type="checkbox"/> Other |

DEVELOPMENTAL SCREENING

At what age level is your child functioning: cognitively _____ motor skills _____

Last Date Tested: _____ By Whom: _____ Where: _____

- Ambulation:**
- | | |
|--|--|
| <input type="checkbox"/> Walks Independently | <input type="checkbox"/> Walks With Assistance |
| <input type="checkbox"/> Walks With Walker/Brace, Etc. | <input type="checkbox"/> Non-Ambulatory |
| <input type="checkbox"/> Uses Wheelchair With Assist. | <input type="checkbox"/> Motorized |
| <input type="checkbox"/> Uses Wheelchair w/o Assist. | <input type="checkbox"/> Motorized |

Transfer Directions:

- | | | |
|---|---|---|
| <input type="checkbox"/> Independent | <input type="checkbox"/> With Assist | <input type="checkbox"/> Equipment Type |
| <input type="checkbox"/> Pivot Transfer | <input type="checkbox"/> 1 or 2 Person Lift | <input type="checkbox"/> Other |

Feeding:

- | | | |
|---------------------------------------|---|--|
| <input type="checkbox"/> Regular Diet | <input type="checkbox"/> No Assist | |
| <input type="checkbox"/> Soft Diet | <input type="checkbox"/> Partial Assist | <input type="checkbox"/> Special Dishes or |
| <input type="checkbox"/> Pureed | <input type="checkbox"/> Total Assist | <input type="checkbox"/> Pureed Finger Foods |

Utensils

Feeding Pump

Child's Name: _____

Hygiene: No Assistance

Partial Assistance

Totally Assisted

Bath Chair or Shower Equipment

Toileting: Fully Toilet Trained

No Assistance

Diapers at Night

Partial Assistance

Diaper Dependent

Full Assistance

Intermittent Catheterization Program

Frequency _____ Technique _____

Independent

Needs Assistance

Bowel Management Program

Child's Name: _____

Monthly Weight Chart

Date / Year	Weight in lbs.	Change +/-	Date / Year	Weight in lbs.	Change +/-
January			July		
February			August		
March			September		
April			October		
May			November		
June			December		

Date / Year	Weight in lbs.	Change +/-	Date / Year	Weight in lbs.	Change +/-
January			July		
February			August		
March			September		
April			October		
May			November		
June			December		

Date / Year	Weight in lbs.	Change +/-	Date / Year	Weight in lbs.	Change +/-
January			July		
February			August		
March			September		
April			October		
May			November		
June			December		

Tips on Preparing to See the Doctor

1. GET READY

- a. Bring any information that you have on your child.
- b. Bring pen/pencil and paper to take notes.
- c. Check your data and be specific about all changes in your child's health status.
- d. Have a list of all medications your child is currently using, including over the counter medications.
- e. Have a list of reactions your child has experienced from any medications; prescribed, or over the counter.
- f. Write all your questions down before calling or visiting the physician.

2. TELL THE DOCTOR

- a. How your child has been doing.
- b. Information about successes and setbacks.
- c. Detailed information about changes and symptoms that are different from your child's normal status.
- d. What you are concerned about.
- e. When the symptoms are changing.
- f. How often and when the symptoms occurred.
- g. What you tried for relieving the symptoms and your child's response.

3. DON'T LEAVE THE DOCTORS OFFICE WITHOUT

- a. Instructions and name(s) for new and old medication(s).
- b. Asking how long the child will be on the medication(s) and whether there are refills.
- c. Asking about possible side effects or cross-reactions of medication(s).
- d. Asking what the child can eat with new medication(s).
- e. Asking if you need an authorization before filling the prescription for your specific insurance provider.
- f. Understanding all follow-up questions including how to report changes in symptoms.
- g. Asking physician if you need a follow-up appointment.
- h. Making the next appointment, if needed.
- i. Informing receptionist if you think that you will need extra time for special accommodations.

Notes from Doctor Appointments

Doctor's Name: _____

Appointment Date: _____ **Appointment Time:** _____

Diagnosis Given: _____

Notes: _____

Doctor's Name: _____

Appointment Date: _____ **Appointment Time:** _____

Diagnosis Given: _____

Notes: _____

Doctor's Name: _____

Appointment Date: _____ **Appointment Time:** _____

Diagnosis Given: _____

Notes: _____

Questions to Ask the HMOs: A Parent's Guide

Equipment

- ◆ I get my wheelchairs (or other medical equipment or supplies) from _____
- ◆ Can I still get them there?
- ◆ What equipment and supply companies can I use?
- ◆ Who has to approve my special equipment supplies?
- ◆ How do I get them?

Nursing

- ◆ If I need long term nursing care, will I be able to get a private duty nurse for my child?
- ◆ Which nursing agencies are providers?
- ◆ I already get home health services from _____
- ◆ Can I still use them?

Speech

- ◆ Can my child still see his speech therapist, _____
- ◆ What speech therapists are available through your plan?
- ◆ Who has to approve speech therapy?

Physical Therapy and Occupational Therapy

- ◆ Can my child still see his OT and/or PT? _____
- ◆ What OTs and PTs are available?
- ◆ Who has to approve OT and/or PT?

Pharmacy

- ◆ Are the drugs my child takes on your plans' formulary (list of drugs)?
- ◆ Are the pharmacies I use on the plans' provider list?

Doctor

- ◆ Is my child's primary physician on your plans' provider list?
- ◆ Are my child's specialist physicians on your plans' provider list?
- ◆ What do I do in order for my child to be able to see a specialist?
- ◆ How can I still use my child's PCP/Specialist if they are not on our plan?

Parents Guide to HMOs (cont.)

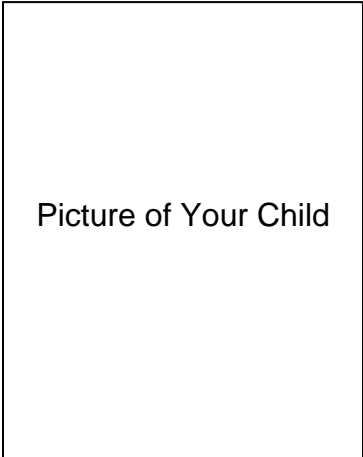
- ✓ Parents: Find out which plan or plans your child's physician is signed up with. Many physicians are signed up with more than one plan.
- ✓ Remember to write down the date, telephone calls, and discussions that you have with the HMOs and Medicaid. This will help you keep track of information.
- ✓ Ask the plan how they handle grievances, prior approvals, and special accommodations.
- ✓ Ask the plan how they handle emergencies.

Remember
*Sign up quickly, before the deadline.
This gives the HMO and you time to
communicate your child's' needs and
plan ahead before the start-up date.*

**Stay in touch with your child's' case manager if you are using a traditional waiver system.
He/she will have current updates and information.**

Describe a Typical Day for Your Child

Use as many pages as you need to describe it and don't forget likes and dislikes, mealtime, bathing, and grooming.



This page should paint a picture of your child. Anyone should be able read this and have a clear understanding of your child's needs and routines. This is important information for all of the people actively involved in your child's life.

1. Describe your child's favorite things to do. _____

2. Write about your child's ability to get along or interact with others. _____

6. Describe things that upset your child and what your child does when upset or when he or she has “had enough.” _____

7. Describe any security or comfort objects your child uses. _____

8. Describe special family activities or customs that are important. _____

9. Describe things to do or say to comfort your child. _____

Care Schedule

TIME	Care Activity
*Evening	

Medication Log

DATE STARTED	DATE STOPPED	MEDICATION	WHAT IT IS FOR	DOSE / ROUTE	TIME GIVEN	PRESCRIBED BY	SIDE EFFECTS

Monthly Supply Log

INFORMATION NEEDED FOR MEDICAL SUPPLIES

Child's Name: _____

Phone: _____

Address: _____

Physician(s): _____

Insurance Company Responsible for Supplies: _____

Policy #: _____

Authorization#: _____

Insurance Phone: _____

Insurance Contact: _____

①

Supplier: _____
Phone: _____
Contact: _____

③

Supplier: _____
Phone: _____
Contact: _____

②

Supplier: _____
Phone: _____
Contact: _____

④

Supplier: _____
Phone: _____
Contact: _____

School Information

Name:

Address:

Phone:

Teacher's Name(s):

School Nurse:

Phone#:

Special Attendant:

Grade/Placement:

Type of Class:

Special Services:

Transportation:

IEP/IFSP:

Goals:

School Concerns:

Future Estate Planning



No one lives forever, not even parents of children with disabilities. Fears about what will happen to your child after you're gone keep you from doing the very thing that will give you peace of mind; *PLANNING*. You fear that your child's quality of life may not be the same as they have now. You also know that it should not be left totally up to their sister or brother to care for them. Sometimes the thought of all of this is so overwhelming that you don't even know where to start.

This section is that starting place. It can be a way to facilitate discussion among your family members or just a way to begin organizing your thoughts and getting them down on paper. You can begin with a less emotional section like personal information before moving on to the difficult task of choosing a Guardian. Guardianship guidelines vary from state to state. Your attorney can advise you, but not all attorneys are familiar with Special Needs Trusts. A list of attorneys who specialize in this area may be obtained through the national, state, or local Arc. Don't forget to update annually, make copies, and give them to all those who should know about your wishes. Planning is a process that takes time, but once you have things decided, you will be able to breathe that sigh of relief knowing you no longer have to worry about the future.

Estate Planning Worksheets

Living Arrangements

Where and in what type of situation would you like to see your child live? Would they live alone or have roommates? What neighborhood? How much supervision would they need?

If currently in a supported living environment, list the following information:

Home Manager _____

Name and Phone Number _____

Second Choice _____

Case Manager _____

Name and Phone Number _____

First Choice of Future Residential Provider _____

Other Service Agencies (Example: Family Resources, Transportation, etc.) _____

Agency Name	Contact Person	Phone Number	Reason Used

Estate Planning Worksheets

Your Legal / Financial Information

Government / Private Benefits / Assistance (example: SSI, Social Security/Disability Insurance)

Type of Benefit _____

Amount _____

Contact Person/Case Worker _____

Department of Human Services Case Worker and Phone Number:

Type of Benefit _____

Amount _____

Other Benefits (currently receiving) (example: transportation, cash subsidies/vouchers, utility subsidies)

Other Benefits your child might be entitled to upon your death (example: Veterans, Railroad)

LIFE INSURANCE

Company _____

Policy Number _____

BURIAL POLICY

Funeral Home _____

Cemetery _____

Estate Planning Worksheets

Will and Estate Plans

Letters of Guardianship have been approved by:

Judge _____ Date _____

Approved Guardian's Name _____

Address _____

Phone Number _____

Relationship _____

Approved Successor Guardians

Name _____

Address _____

Phone Number _____

Relationship _____

Name _____

Address _____

Phone Number _____

Relationship _____

If a guardian has not been appointed, list in order of preference the people who you would like to serve as guardian, should guardianship prove necessary in the future. Include name(s), address, phone number, and the person's relationship to you.

Estate Planning Worksheets

Trusts

“Trusts are flexible, legal documents by which one party leaves assets to another party (a trustee) to be used for the benefit of another person, charity, and so on. The trust instrument gives specific instructions as to how to pay out the assets. Trusts are not only for the wealthy. They represent a way to withhold assets from someone who may not be old enough, have enough experience, or have the ability to make wise decisions...”

“Several different trust options are now available that allow provision for people with disabilities without affecting their eligibility for Medicaid and SSI. In general, these trusts cannot be used to pay for support and care (necessities of life) without jeopardizing an individual’s eligibility for Medicaid and SSI. It is also worth remembering that it does not take a great deal of money to pay only for supplemental items or luxuries. Thus, the trust doesn’t need to have a great deal of money in it to accomplish its purpose.”

From: Estate and Future Planning: Handbook for Ohioans with Disabilities and Their Families, David A. Zwyer, Esq., 2004.

Attorney / Agency / Company Managing the Trust

Address _____

Phone Number _____

Location of a Copy of the Trust _____

List agencies Notified About the Trust _____

LAST WILL AND TESTAMENT

“A document that might be used to more fully explain the intent of a person making a Will is called a Letter of Instruction. It may make sense to more fully express one’s wishes in such a Letter of Instruction than is really proper for a legal instrument such as a Will.”

From: Estate and Future Planning: Handbook for Ohioans with Disabilities and Their Families, David A. Zwyer, Esq., 2004.

Attorney _____

Location of a Copy of the Will _____

Durable Power of Attorney _____

*Adapted From Website PDF Form: Families Empowering Families,
The Arc Hamilton County, Revised, January, 2003*

Guardianship in New Mexico for People With Disabilities



In New Mexico, it is generally assumed that when young people reach 18 years of age, they are adults and can legally make their own decisions, even if they have a disability.

When a person lacks the ability to understand information and communicate decisions, or to manage their own affairs, the person may be considered *incapacitated*. A guardian is a person who has been given the right, by a court order, to make decisions for an *incapacitated* person and to supervise certain aspects of their life.

Most adults with mental or physical disabilities can make some or all of their own decisions. There is no law that requires people with disabilities to have a guardian. Even if an adult is incapacitated, no one else can act as their guardian unless they have been appointed by a court order.

Guardianship can help protect and assist an *incapacitated* person. A parent, relative, friend, or other interested person can ask the court to appoint a guardian for someone if they believe that person is *incapacitated* and in need of a guardian.

A person's right to make their own decisions is limited when they have a guardian. For this reason, the law sets standards for appointment of guardians and their powers.

The court will not appoint a guardian unless it has been shown by "clear and convincing evidence" that the person cannot make major life decisions or care for their personal welfare.

The guardian's powers should be limited to those decisions that the *incapacitated* person cannot make for themselves.

Important Terms

AN ADVOCATE is a person who assists the individual in making decisions that affect the quality of life. The advocate plays an active role in helping the individual self-advocate in all aspects of his/her life.

BEST INTEREST is a course of action that maximizes what is best for the individual and which includes consideration and support of the individual's wants/vision/needs, which is least intrusive/restrictive, and which is most normalizing.

CAPACITY is an individual's ability to make and communicate decisions about, and manage, activities of daily living, healthcare, personal affairs, and/or financial affairs and property. An individual may lack capacity for some but not all areas of functioning depending upon his/her ability to understand and appreciate the consequences of his/her decisions. Individuals are assumed to have capacity unless a legal process has taken place to determine incapacity.

A CONSERVATOR is a person appointed by a court to manage the property and/or financial affairs of someone who is unable to do so himself/herself.

A GUARDIAN is a person appointed by a court to make decisions for someone who is unable to make his/her own decisions about such matters as healthcare and residence.

A PETITIONER is the person seeking legal guardianship of an alleged incapacitated adult or a minor child.

A WARD is an incapacitated person who may need the assistance of a guardian.

A FULL or PLENARY GUARDIAN is responsible for all major decision-making for the incapacitated person. Even with a full guardianship, the guardian must consider the wishes of the incapacitated person. A separate hearing must take place for decisions about sterilization or termination of pregnancy.

A LIMITED GUARDIAN is a person appointed by a court if an individual is able to make some, but not all, personal decisions that are time-limited. The court order will say which decisions the guardian is responsible for making. The individual retains all other decision-making powers.

A TEMPORARY GUARDIAN can be appointed for up to 60 days if a rapid decision must be made regarding the health or safety of an incapacitated person.

A TREATMENT GUARDIAN is appointed by a court to make decisions regarding *mental health medications and mental health treatment only* under the Mental Health and Developmental Disabilities Code, rather than under the Probate Code, as is the case for other types of guardianships. Treatment guardianship is for a period specified by the court

in the guardianship order, not to exceed one year. If a treatment guardian is needed for a longer period, then a new guardianship petition must be filed.

A TESTAMENTARY GUARDIAN is named and appointed in a will of the legal guardian or parent. The guardianship goes into effect after the parent or legal guardian dies and after the will has been accepted in court. The appointment will be terminated immediately if the incapacitated person gives a written objection to the court.

A GUARDIAN AD LITEM is a person appointed by a court to protect and ensure the rights of the individual in court proceedings. This person is always appointed to represent the individual in guardianship proceedings. The Guardian Ad Litem may recommend action to the court based on his or her assessment of the individual's best interest.

GUARDIANS SHOULD CONSIDER THE INDIVIDUAL'S WANTS AND NEEDS.

Many New Mexicans with developmental disabilities have guardians who make decisions about where they live, how they spend their money, and other fundamental life decisions. Remember to examine the role of guardianship in the life of the individual with developmental disabilities. Look at the alternatives to different types of guardianship. Support people with developmental disabilities in learning how to use their own voice in making decisions and advocating for themselves.

THE GUARDIANSHIP PROCESS

Other methods of providing support to the incapacitated person should be considered before the guardianship process is used. Examples of other ways to provide assistance are through the use of a power of attorney or a representative payee.

Once the decision is made that a person may need a guardian, anyone (a parent, spouse, sibling, or other relative, friend, case manager, or a representative of the provider agency) can ask the court to appoint a guardian.

- ◆ After a Petition and other necessary papers are filed in the appropriate District Court and the filing fees are paid, the Court will set a date for a hearing on the Petition.
- ◆ At, or before the hearing, the court will require reports from a qualified healthcare professional, a Visitor, and the Guardian Ad Litem. The qualified healthcare professional can be an MD, a psychiatrist, psychologist, or a nurse practitioner. The healthcare professional must examine the proposed Ward and submit a written report to the court describing the proposed Ward's level of intellectual and developmental functioning, and whether there may be a deficit in any area.

- ◆ A Visitor is usually a social worker or a similar individual who must interview the proposed Guardian, visit the proposed Ward's home, and report to the court on the proposed Ward's needs and the appropriateness of the Guardianship.
- ◆ The court will appoint a Guardian Ad Litem to represent and protect the rights of the individual for whom guardianship is proposed. The Guardian Ad Litem must visit the incapacitated person before the hearing. It is the Guardian Ad Litem's role to ensure that a guardian is appointed only if necessary and guardianship is in the person's best interest.
- ◆ Everyone listed above, including the incapacitated person and the proposed Guardian, will be notified and is entitled to attend the hearing. The healthcare professional is required to send a written report. The court may ask anyone to testify and/or answer questions about the proposed Ward's limitations and capacity for self-care. The court will not grant the Petition unless the Petitioner proves the allegations of the Petition with clear and convincing evidence.
- ◆ The hearing can be held in the county where the proposed Ward lives and there is an option for a jury trial.
- ◆ If the court agrees that a Guardian is needed, the court will issue an order appointing a Limited or Plenary Guardian.
- ◆ The Guardian must submit an annual report to the court documenting how the Ward is doing and the Guardian's work, and efforts on the Ward's behalf. The report is due on or before the anniversary of the date the Guardianship was granted. The court is authorized to assess a fine for filing this report late.
- ◆ To initiate a change in or a termination of the guardianship, the Ward or other interested party may write to the court requesting the change or petition for the requested relief.
- ◆ Regardless of the type of guardianship ordered, an incapacitated person retains their human, civil, and constitutional rights except for those limits specified in the Order. These rights cannot be abridged, modified, or violated by a Guardianship Order.

Resources

NM Developmental Disabilities Planning Counsel
Office of Guardianship
(800) 311-2229 or (505) 476-7324 (TTY)

The Arc of New Mexico Guardianship Program
3500 Comanche NE, Bldg. G, Albuquerque, NM 87110
http://www.arcnm.org/index.php/get_help/summary/C59/

Disability Rights
1720 Louisiana Blvd. NE
Suite 204
Albuquerque, NM 87110
(505) 256-3100
(800) 432-4682
(Voice and TTY)
FAX: (505) 256-3184
email: info@nmpanda.org
website: <http://www.nmpanda.org>

SUPPLEMENTAL RESOURCES

- ◆ **Adult Protective Services (APS) (505) 841-4500 or (866) 654-3219:** APS receives complaints regarding adult abuse, neglect, and exploitation. If APS substantiates that an adult needs a guardian, APS will file in the District Courts throughout the state.
- ◆ **The Developmental Disabilities Planning Council's Office of Guardianship (800) 311-2229:** The Office of Guardianship receives funding from the Legislature for training and other programs that assist Medicaid individuals to obtain guardianship. The funding pays for families/corporate guardianship providers to become a legal guardian. The Office of Guardianship provides written materials such as "The Handbook for Guardians and Conservators: A Practical Guide to New Mexico Law" and "Alternatives to Guardianship and Conservatorship." The Office of Guardianship can provide instruction to individuals about being a guardian; seeking alternative routes, and training case managers and others such as providers, attorneys, judges, and hospital personnel. The Office of Guardianship can provide a list of available corporate guardianship agencies that they contract with and can be contacted to provide guardianship of last resort for individuals who have no family or friends able or willing to provide guardianship.
- ◆ **Lawyer Referral for the Elderly Program (LREP), Becky Jiron, (505) 797-6005 or (800) 876-6657:** The LREP will assist in finding attorneys that will provide services pro-bono. Attorneys donate their time and will help in preparing the necessary paperwork for legal proceedings. To be eligible, the individual must be 55 years or older and must

be a resident of New Mexico. The LREP provides legal services to the State Agency on Aging by contracting their services.

- ◆ **Disability Rights (Formerly Protection and Advocacy, P&A) (505) 256-3100 or (800) 432-4682:** The P & A promotes, protects, and enhances the rights of individuals with mental illness and/or developmental disabilities. They do not charge for their services.
- ◆ **The State Bar of New Mexico (505) 797-6000:** The State Bar provides legal services to the elderly. Once a provider is contacted, they will refer individuals to the Lawyers Care Program, who will then assist the individual with services that they may need. They can assist adults with a general referral program with a thirty minute consultation for a small fee.
 - ◇ The providers are: Northern New Mexico Legal Services, Southern New Mexico Legal Services, also providing services to the Navajo Nation, and the Albuquerque Bar Association Volunteer Lawyers Program, serving Bernalillo County, and other providers listed below. State Bar resources may be contacted as follows:

Community & Indian Legal Services of Northern New Mexico

Gallup Office: (505) 722-4417 or (800) 524-4417

Las Vegas Office: (800) 980-1165

(Referrals to the Guardianship HELP Line Law Access)

Santa Fe Office: (800) 980-1165

Referrals to the Guardianship HELP Line Law Access

Santa Ana Pueblo: (505) 867-3391 or (800) 867-3452

Southern New Mexico Legal Services

Clovis Office: (575) 769-2326

Las Cruces Office: (575) 541-4800 or (800) 376-7665

Roswell Office: (575) 623-9669 or (800) 376-7665

Dine-People's Legal Services, Inc.

Crownpoint Office: (505) 786-5277

Shiprock Office: (505) 368-3200

(For Children Only)

Indian Pueblo Legal Services, Inc.

Rio Grande Pueblos Office: (505) 867-3391

(For the Native American Program Only)

Other Resources

Senior Citizen's Law Office: (505) 265-2300

Albuquerque Bar Association Volunteer Lawyers: (505) 256-0417 (For Children Only)

*Information Compiled From Developmental Disabilities Support Division (DDSD)
and Protection and Advocacy's Website*

Strategies for Managing Life

Parents' Top Twenty Strategies for Managing Life

by Kate Scorgie, PhD and Lorraine Wilgosh, PhD



1. Celebrate my child

Celebrar a mi hijo/a

What this means to my family

Qué significa esto para mi familia

- ◆ This is important – and hard – for families to do as soon as they are ready and to keep it up as the child grows up
- ◆ Grief is natural – while a lot of the feelings we experience are “yucky,” they do serve a purpose. Give yourself permission to experience them in your own way. Honor how others in your family and those who are in your close circle of support experience them.
- ◆ One Mom in the article talks about this being an important strategy to deal with the temptation of seeing your child as a label. This may mean seeing your child as a child first and recognizing his/her wonderful gifts.

Ideas I can try

//

Ideas que puedo usar

- ◆ Write or record a letter to your child describing why you celebrate who he/she is.
- ◆ Ask others in the family to write letters as well.

Ideas we came up with today:

2. Choose to focus on what's going right

Concentrarme en lo que va bien

What this means to my family

Qué significa esto para mi familia

- ◆ These two strategies go hand-in-hand because you need to see the good stuff that your child brings to your life before you can celebrate.

Ideas I can try // Ideas que puedo usar

- ◆ Make a scrapbook that highlights what’s going right and keep it on your coffee table.
- ◆ Take time to look at the scrapbook when things don’t feel like they’re going right.
- ◆ Have a party to celebrate an accomplishment or passage through a hard time.

Ideas we came up with today:

3. Get beyond the “why?” to the “how?” **Pasar más allá del “¿por que?” para llegar al “¿cómo?”**

What this means to my family **Qué significa esto para mi familia**

- ◆ One parent described this as a period of no growth for her and her family. She advises that the sooner you can say, “This is how it is -- Let’s go forward from here,” the better it is for everyone.

Ideas I can try // Ideas que puedo usar

- ◆ A lot of parents find that a good way to move beyond the “whys” to the “how” is to set up short and long term goals for their family.
- ◆ Training and meeting with other families are other great ways.

Ideas we came up with today:

4. Appreciate what my child contributes to others **Apreciar lo que mi hijo/a puede dar a otras personas**

What this means to my family

Qué significa esto para mi familia

- ◆ How do others learn and benefit from your child? Think specifically about your child’s family (especially brothers/sisters), classmates, children at your child’s school, and the community.

Ideas I can try // Ideas que puedo usar

◆ Add contribution experiences to your scrapbook.

Ideas we came up with today:

5. Trust my instincts

Confiar en mis instintos

What this means to my family

Qué significa esto para mi familia

- ◆ Remember, you are the one who knows your child best.
- ◆ Think about how many of you knew something just wasn’t right with your child’s health but kept being told by the doctors that everything was fine...until they finally figured it out.
- ◆ Sometimes, parents believe something should be done differently with their child’s educational program but either don’t speak up or compromise because they believe the school staff are the experts. This is especially true for certain cultures.

Ideas I can try // Ideas que puedo usar

◆ A lot of parents use friendly language to assert their concerns. For example, “My Mommy’s instincts keep telling me that something just isn’t right.”

Ideas we came up with today:

6. Don’t go it alone: ask for help

No lo haga sola/o: pida ayuda

What this means to my family

Qué significa esto para mi familia

- ◆ One parent in the Journey article shared that the only way you will get help is by asking. As long as people think you're okay, they leave you alone.
- ◆ David Zarazua, DARS Division for Blind Services Regional Director for El Paso, once shared a quote at a family conference that fits this strategy very well: "We are all angels with but one wing; the only way we can fly is to hold onto each other."

Ideas I can try // Ideas que puedo usar

- ◆ Formal and informal parent networks
- ◆ Get to know other families that have something in common with you.
- ◆ Nothing seems to work better than those "parking lot" or "sideline" referrals we pick up while talking with other parents we find are in the same boat as us.
- ◆ Join family groups and listservs.
- ◆ Attend trainings where other parents will be.
- ◆ Barter with some of your friends who have children with disabilities – you keep their children for a period of time; they do the same for you.
- ◆ Go to a professional counselor.

Ideas we came up with today:

7. Reassess success

Evaluar los éxitos

What this means to my family

Qué significa esto para mi familia

- ◆ One parent advises that you have to learn to come up with your own definition of what a successful child is. You have to throw out the old definitions. Success isn't always that our children grow up, get married and have a good job.

Ideas I can try // Ideas que puedo usar

- ◆ Spend some time around people who have similar disabilities as your child, especially those who are further down the road than your child.

Ideas we came up with today:

8. Utilize planned perseverance

Utilizar perseverancia en lo planeado

What this means to my family

Qué significa esto para mi familia

- ◆ Many families try to periodically review stuff already have learned and applied just to make sure you still got it. Stephen Covey calls this strategy “sharpening the saw.”
- ◆ You need strategies to help you find the energy to tell your story over and over again each time you begin a new school year or begin working with a new professional.

Ideas I can try

//

Ideas que puedo usar

- ◆ Even if you don’t attend support groups or parent training regularly, try to from time to time so that you can refresh and learn what progress has been made in understanding your child’s condition.
- ◆ A lot of parents have found making a scrapbook that tells a story about their child (including explaining their disability, describing their likes and dislikes, etc.) is a great way to keep from having to tell their story over and over.
- ◆ Use the Child Profile that makes my child shine.

Ideas we came up with today:

9. Be a parent first

Concentrarme en ser un padre o una madre primero

What this means to my family

Qué significa esto para mi familia

- ◆ This may mean making sure you don't get so busy being the advocate, social worker, teacher, driver, medical director, etc. that you don't have time to be Mom or Dad.
- ◆ Being a parent first is not only the only way to keep yourself energized, it's what your kid needs most from you.

<i>Ideas I can try</i>	//	<i>Ideas que puedo usar</i>
------------------------	----	-----------------------------

- ◆ Clear the schedule.
- ◆ Make time for family fun night.
- ◆ Spend time with each of your kids doing nothing but being together. One Mom once shared that she has a regular date with her typically-developing son.
- ◆ One parent put it this way, "Being a family first is our priority and we protect our time together."

Ideas we came up with today:

10. Keep my sense of humor

Mantener mi sentido de humor

What this means to my family

Qué significa esto para mi familia

- ◆ One parent I know has three boys, all of whom have disabilities. They've chosen a family motto to help them keep their sense of humor: "Why Be Normal, That's Boring!"

<i>Ideas I can try</i>	//	<i>Ideas que puedo usar</i>
------------------------	----	-----------------------------

- ◆ Sometimes, the only ones who can truly appreciate the humor in what you go through are other parents in the same shoes as you – another good reason to spend time with other parents of kids with similar issues.

Ideas we came up with today:

11. Be flexible day to day

Ser flexible cada día

What this means to my family

Qué significa esto para mi familia

- ◆ The parent in the article talks about “White Days” (good health), “Gray Days” (in-between) and “Black Days” (bad health)

Ideas I can try // Ideas que puedo usar

- ◆ Gray or Black Days are great days to spend time together looking at the scrapbook of celebrations and successes.

Ideas we came up with today:

12. Give myself a “time out”

Darme tiempo para mi solo/a

What this means to my family

Qué significa esto para mi familia

- ◆ The parent in the article said she sets up one night a week that is hers. That way, she always has something to look forward to that gets her through some of the rough spots. That night, she goes out with girlfriends who always seem to talk about how much they really need this one night because of the stress they have with their so-called “normal kids.” She’s showing her sense of humor by commenting that if they need one night, she probably needs three.

Ideas I can try // Ideas que puedo usar

- ◆ Don’t feel like you could squeeze in one night per week? You’re not alone. How about trying to get in a bubble bath or sitting outside after the kids (and husband, dog, fish, and friends) are asleep
- ◆ Barter with some of your friends who have children with disabilities – you keep their children for a period of time; they do the same for you.

Ideas we came up with today:

13. Allow myself “ups” and “downs”

Permitirme “subidas” y “bajadas”

What this means to my family

Qué significa esto para mi familia

- ◆ Countless Moms have said that they need someone they are close to who will remind them from time to time that it’s okay to feel down because something just went wrong. The best advice a parent said she got from another Mom was that “I owed it to myself to allow myself to feel the highs and the lows.” She said that she finds that when she does, she spends much less time stuck in the lows.

<i>Ideas I can try</i> // <i>Ideas que puedo usar</i>

- | |
|---|
| <ul style="list-style-type: none">◆ Talk with someone you’re close with to play this role for and with you.◆ Help your loved ones know what you need by saying something like, “I’m going to share something with you and what I really need is for you to give me a hug and say ‘there, there, let it all out, – don’t try to fix it, I just need to feel this for a moment before I move on.’” |
|---|

Ideas we came up with today:

14. Remember to nurture our marriage

Acordarme de mantener nuestro matrimonio

What this means to my family

Qué significa esto para mi familia

- ◆ If you’re not married, read this to mean nurture your relationship with whomever you get your primary support from. A single mother shared that as a single parent, she has a few close friends who were in similar situations. They were each other’s support and understood that they needed to take every bit as much care of their relationship as a couple in a marriage would.

Ideas I can try // Ideas que puedo usar

- ◆ Set up a regular date.
- ◆ Take time to talk about something other than the kids, bills, school, and work/life stresses.
- ◆ Remember to be affectionate with each other – touch is powerful and we all need it.

Ideas we came up with today:

15. Be a family

Ser una familia

What this means to my family

Qué significa esto para mi familia

- ◆ A strategy shared earlier is to make sure your family schedule isn't loaded down with "programming." For the parent in the article, she said this meant going on their annual trip to the mountains. It also meant having breakfast together every day.

Ideas I can try // Ideas que puedo usar

- ◆ Set aside 3-5 minutes every morning to have a family get together. For one family, they did this before everyone headed off in their separate directions. They said a quick prayer, hugged each other (usually playfully done as a group hug) and then went their separate directions.

Ideas we came up with today:

16. Balance time together with each of my children

Dividir el tiempo con cada uno de mis hijos/hijas

What this means to my family

Qué significa esto para mi familia

- ◆ A wise man once shared that each of our kids are buckets – they need to each be filled up with lots of love.
- ◆ The mother in the article shares how one day her son asked her point blank if she liked her son with the disabilities better than the other children because she was always spending time with him and holding him. This kid was able to say something that almost any brother or sister with a disability feels.
- ◆ This strategy is similar to a story once shared about three grown sons speaking at their mother’s funeral. Before she died, she slipped each of them a note that told him, “You are my favorite child.” As each of these men spoke about their mother in front of the other grievers, they were surprised to hear the other share how they saw their mother as their best friend – someone who had always made them feel very special. Wow, isn’t that what we want for each of our kids?
- ◆ We, as parents, can’t wait for our kids to tell us they feel “less loved” or for our own funeral to see how they viewed our affection towards them. We need to figure out how to balance time with each of them so they know how very much loved each of them are.

<i>Ideas I can try</i> // <i>Ideas que puedo usar</i>

- | |
|--|
| <ul style="list-style-type: none"> ◆ How about that date night? ◆ Build into the nightly routine where you can spend some time with each of your kids – all alone with them. |
|--|

Ideas we came up with today:

17. Know what I want and go for it

Saber lo que quiero y conseguirlo

What this means to my family

Qué significa esto para mi familia

- ◆ The mother quoted in the article says something that we can all stand to live by...Don’t take ‘no’ as the final answer; take it as a definite ‘maybe’ and go from there. A lot of times, people tell us ‘no’ because they think we’re going to go away. She recommends you do your homework, are well prepared, and make a legitimate argument. She’s found out what many other parents have learned – people will listen when you take this tack.

Ideas I can try // Ideas que puedo usar

- ◆ One professional helps families figure out how to begin this by talking about right brain (emotional) and left brain (logical) thinking when they are figuring out what they want and how to go for it. The parents learn to ask themselves, “Am I saying this ‘right brain’ or ‘left brain’ and can even give each other secret codes in meetings by simply saying ‘left brain.’

Ideas we came up with today:

18. Be resourceful: find ways to be understood

Buscar cómo me puedan entender

What this means to my family

Qué significa esto para mi familia

- ◆ A mother shared how her neighbor spent the morning with her and her daughter videotaping them to show what it took for the parents to care for the little girl while she was spasming. Showing the videotape to the professionals, who just couldn’t get it, helped them understand their situation and what supports they needed.
- ◆

Ideas I can try // Ideas que puedo usar

- ◆ Videotape, record, or invite someone to your home for a while so that they can see first hand what you are trying to help them understand.
- ◆ Ask others to share. Sometimes people need to hear it said another way from another person before they understand.

Ideas we came up with today:

19. Connect with other parents

Conectarme con otros padres

What this means to my family

Qué significa esto para mi familia

- ◆ Most parents find it best when they go to other parents first to talk about something they're having trouble with. Again, this doesn't have to be through a formal support group.

Ideas I can try

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Ideas que puedo usar

- ◆ Think about what we discussed in Strategy 6:
- ◆ Formal and informal parent networks
- ◆ Get to know other families that have something in common with you.
- ◆ Nothing seems to work better than those “parking lot” referrals we pick up while talking with other parents in the same boat as us.
- ◆ Join parent groups and listservs.
- ◆ Attend training where other parents will be.
- ◆ Barter with some of your friends who have children with disabilities – you keep their children for a period of time; they do the same for you.
- ◆ Go to a professional counselor.

Ideas we came up with today:

20. Value the journey

Valorar el camino que nos queda

What this means to my family

Qué significa esto para mi familia

- ◆ Take to heart what the mother in the article said about valuing her journey with her son. She shared that when she looks back, she sees what a wonderful teacher he has been to her. She can also see what a wonderful impact he's had on so many lives. When he was younger, she felt driven to learn everything right then, get everything perfect right then. With time and experience, she's found that while her son grows, she does too.

Ideas I can try

//

Ideas que puedo usar

Communication - Messages We Give and Get

As you begin to gather the information you need to help your child, you will meet and interact with an overwhelming number of professionals. Some will communicate with you simply, easily, and with human warmth and compassion. Others, while competent, may not be good communicators. While you may not be able to change the people with whom you come in contact, you can improve your own communication skills. As you become a more effective communicator, you will be better able to relay and receive information that is critical to the growth, development, and well-being of your child and family.

ENHANCING COMMUNICATION

We communicate in many ways and with many different people. Good communication becomes critical when we're exchanging relevant information about our child. By learning to recognize what blocks and enhances communication, we can improve nearly every situation involving our children.

Skills that Enhance Communication

- *Concentration*
- *Interest*
- *Reporting*
- *Understanding*
- *Retaining of Information*
- *Explaining*
- *Interpreting*

BLOCKING COMMUNICATION

As you help your child to grow and develop, you will gain valuable knowledge, form educated opinions and develop certain instincts regarding what is best for you, your child, and your family. *You have a right to be a partner in the decisions that are being made* and that means being encouraged to give, as well as receive information.

There are many things that can block communication. As you become aware of what those things are, you can begin remove some of the barriers to good communication.

What Can Block Communication?

- *Emotions, Feelings*
- *Attitudes*
- *Body Language*
- *Inequality*
- *Lack of Respect*
- *Withholding Information*
- *Jargon (Medical, Technical)*
- *Lack of Knowledge*

to

ATTITUDES DO AFFECT COMMUNICATION

Perhaps as important as any of these skills is your own attitude. One parent has found that it helps tremendously if she initiates the conversation.

Think about a specific situation where communication was especially difficult for you. Now try to remember what was making communication difficult or interfering with the exchange of information. Then, think about some things that you could have done (or will do next time) to improve or open up communication in this situation.

WHAT, WHEN, AND TO WHOM

When it comes to family, friends, casual acquaintances, strangers, fellow parishioners, or neighbors – what, when, and how much you communicate is a personal decision.

Encounters with strangers are always hard situations. It is a very personal decision on how much you want to share. There are times when you may feel the need to give a detailed explanation and others not much at all.

One couple together wrote a beautiful piece titled simply “Katie is Katie” to distribute to members of their church. In it, they chose to tell a little about Katie’s rare disorder. But the overriding message was about Katie – who she is, what she loves, and how she lives. She is first and foremost beautiful, dark-eyed, brown-haired, giggly Katie who looks fragile but loves to roughhouse, whose vision is impaired, but would love to explore your face with her fingertips. Most of all, the message they sent was, “Don’t be afraid to ask.”

Another parent says that she’s most comfortable deciding first why people are curious. “If they’re genuinely concerned about us and care about us – I’ll tell everything to help them understand. But if it’s idle curiosity, I feel no need to satisfy it...and I don’t.”

Just remember, there is no magic formula, no right time, or exact amount of information that should be given. When the exchange of information is not critical to your child’s growth and development, the only rule to follow is - *Whatever makes you comfortable.*

PARENT-PROFESSIONAL COMMUNICATION:

The information you give to and receive from professionals is of vital importance to your child’s development and your family’s well-being. *It is also important to remember to ask questions if you don’t understand.* Remember to use the “w” and “h” words to get your questions answered and to open the door to conversation.

Helpful Words and Phrases

- **What** do you think about this?
- **How** will we accomplish that?
- **When** will that happen?
- **Where** is my child developmentally?
- **Who** will provide that service?
- **Why** are you recommending that?

You have valuable information and insights about your child that no one else has. You can answer questions that will enable people to know your child as an “individual,” his or her dislikes, medical history, personality, and countless other personal characteristics and strengths that make your child so rare and wonderful.

You can also serve as the communication link between the professionals from different agencies and services that are all assisting you. Remember, you’re the key person on your child’s team, and your observation, questions, and opinions are important. A good working relationship is essential, showing respect between all those involved.

Adapted From The Family Information Network: Family Child Learning Center, Tallmadge, OH

Communication Log

Use the following log for any communication you would like to document. This will help you communicate effectively. Keeping a log will also help you document information accurately. Example: On this date, at this time, Jane said this.....

(Use This Log for Phone or Personal Communication)

Date / Time	Message / Concern / Reason for the Discussion	Time of Call Back / Who & What Said	Outcome / Results / Follow-up if Needed

Taking Care of Yourself Enables You to Take Care of Those You Love

When we're busy taking care of others, one of the very first things we neglect is taking care of ourselves. However, you probably know already that it's when we take care of our own needs that we can most effectively, compassionately, and thoroughly care for those around us. So take some time *today* to do something just for you. It doesn't have to require a babysitter, and it doesn't have to take up much of your time. This simple act of doing something for yourself can work to make you feel stronger, restore your sense of peace, and fill you with hope for what lies ahead.

- ◆ Take a long walk
- ◆ Check out a yoga video or DVD from your local library, and make time to do it twice a week
- ◆ Read a fiction book or short story that you can totally lose yourself in
- ◆ Write your life story
- ◆ Daydream
- ◆ Try a new recipe
- ◆ Get a babysitter and go to a movie alone
- ◆ Write a letter to a friend
- ◆ Smile
- ◆ Set the timer, close your eyes, and breathe deeply for five minutes
- ◆ Read a magazine
- ◆ Clean your house – it can be a great stress reliever
- ◆ Sit outside and breathe fresh air
- ◆ Get up fifteen minutes early so you can linger over a cup of coffee
- ◆ Swap play dates with a neighbor so you can each enjoy a few minutes of solitude
- ◆ Bake a scrumptious dessert just for you
- ◆ Re-read something that has been especially encouraging to you
- ◆ Write in a journal
- ◆ Go to a park and sit on the swings with your kids
- ◆ Go to bed an hour early
- ◆ Watch the sunset
- ◆ Listen to soothing music
- ◆ Grow something, such as a houseplant or fresh herbs
- ◆ Sit with a cup of hot chocolate or some hot tea
- ◆ Surround yourself with pictures of the people you love and things you care about
- ◆ Give yourself permission to say “NO” to something you really don't have time for or are not interested in
- ◆ Say “YES” to something you'd really like to without feeling guilty!
- ◆ Express your creativity
- ◆ Lend a hand to someone in need
- ◆ Hug your kids

The Power to Choose - Building Family Strengths

When faced with the challenge of raising a child with special needs, many parents describe the “loss of control” they feel, both over the situation and over their lives in general. Choice becomes an important issue. Parents did not “choose” for their child to have special needs.

As parents of a child with a disability, you have experienced the most profound loss of choice. If only you could choose, of course, you would choose perfect health and an ordinary life for your child. Faced with this loss, even the smallest decisions can be overwhelming.

To restore some of the power comes the ability to choose. The information that follows helps you experience the rewards that come making informed, effective decisions – the right decisions – on the behalf of your child.

Identifying the Problem

One of the trickiest things about decision-making is that not everyone sees the problem in the same light. So the first step is to define the problem with all of the other people involved or concerned. Professionals, family, and friends can all be consulted and will bring to this step a different perspective.

Take advantage of the many caring and concerned professionals who believe the family is central to decision making. Encourage family members to express ideas freely and openly, and most importantly, use your communication techniques to define your situation clearly.

Listing the Options

This step is really a “brainstorming” exercise, and no option should be discarded at this point. The idea is to identify as many solutions as possible.

Possibilities

Investigating the possibilities increases your chances for successful resolution. During this step you will narrow the choices or options to only those that are reasonable and workable.

Be sure that when you are considering the practicality of the options you take into consideration the feelings or opinions of anyone who may be associated with the solution or be required to participate in the plan of resolution. This includes family, friends, support professionals, and your child.

Choosing From Your Options

Begin narrowing your options to those that were practical, logical, and workable. All of the steps in the decision-making model have been leading to this one: Choosing the most appropriate option based on what is best for you, your child, and your family. During this step, it is important that you have confidence in your decisions, be assured that you have the right to choose, and be persuasive and persistent in your efforts to educate and sensitize other people to the needs and priorities of your child and family.

Planning Your Work

Once you have selected your option you will begin the work of putting your plan into action. Many parents find that it helps tremendously to break down long-range goals into daily objectives. It is very important during this stage that you allow enough time for your plan to work. Decide what a reasonable length of time would be to allow for change or progress. Decide ahead of time what your definition of progress is. Sometimes, if a plan doesn't work immediately, we can become discouraged and abandon it for another option. It may be simply that your plan needs more time or some adjustment to produce the results you desire.

Evaluation

How well is the plan working? Is it meeting your goals as you had identified them? Only through periodic evaluation will you be able to determine the effectiveness of your plan or know when to move on to another.

Remember

Defining problems in terms of action to be taken helps in determining solutions. While your child is very young, you will be making decisions for him or her. But at some point in time, your child should have a voice in this process. When that time comes, remember to include your child in all discussions and be prepared for some surprising options.

Professional support persons may not always choose the same option that you will. Have confidence in your ability to choose for your child and family. Above all, be sure to respect your child's individuality and rate of growth and learning when determining any timelines for your plan.

Every family must make decisions, some very difficult, regarding their child's welfare. But when your child is at risk for or has a developmental delay, there are more decisions to make and the consequences generally are more critical to your child's growth and development. Our responses enable us to be good monitors of our child's progress, and allows us to choose and build a rich and rewarding life for our children and ourselves.

Adapted From the Family Information Network: Family Child Learning Center, Tallmadge, OH

The Impact of Childhood Disability: The Parent's Struggle, Pain, and Healing

by Ken Moses, PhD

Dr. Moses is a psychologist who has devoted himself to helping people deal with crisis, trauma, and loss. He is a nationally renowned speaker, author, and clinician who has focused much of his work on parents of children with special needs and disabled adults. He has faced deaths, life threatening illness, disabilities, and other major traumas in his own family and life. He continues to help people sort out their lives after experiencing loss and struggles with the same issues himself.

Children bring to us hope of dreams yet to be fulfilled from the moment they come into our world. Many will say that the most rewarding part of parenting is helping your child in his quest to become...to grow and develop, to discover and share, to try and to succeed. Parents attach to their children through heartfelt, core-level dreams and projections into the future. Quite often, the dreams are such that childhood disability, not the child, shatters those dreams. They must go on with their lives, cope with their child as he or she is now, let go of lost dreams and generate new, more attainable dreams. Recovering is part of the parent's ability to face the complicated, draining, challenging, frightening, and consuming task.

For the parent of an infant with a developmental delay, helping your child to grow can be an overwhelming challenge.

To do all this, "the parent must experience the process of grieving." Parents of children with disabilities are often grieving that loss. Within this section you will read about some of the emotions more commonly experienced after learning that your child's development may not follow an ordinary pattern. As you identify and acknowledge your feelings, you can begin to use some of the coping strategies suggested in this chapter.

Dr. Moses states that grieving is the process where a person moves from one stage to another at any given time by any kind of trigger. As part of that grieving process they experience and manifest the feelings of denial, anxiety, guilt, depression, anger and/or fear. Many parents report that the diagnosis was the beginning of a range of emotions they would eventually experience. They are honest reactions and valid responses to your own personal circumstances. Feelings of these various states may be used in surprisingly positive ways when the feelings are fully shared; in a constructive way, such as in the development of parent/professional partnerships which may become essential to the welfare of the child.

The Feeling States of Grieving

Denial

Some parents say that they had a feeling, long before the diagnosis was made, that “something was wrong.” But until the confirmation of their fears, they denied those feelings. This type of reaction is a very healthy emotion. It gives you time to accept, to adjust, and to make plans. It can also protect you from too much pain. Most people routinely shield themselves with such thoughts as “The terrible things that happen to other people can’t happen to me, because...” This works fine as long as nothing terrible happens, but when it does, no one is prepared to deal with it. This is where denial in the service of grieving comes in. Denial buys the time needed to blunt the initial impact of the shattered dream, to discover the inner strengths needed to confront what has really happened, and to find the people and resources needed to deal with a crisis for which one could not be prepared.

Dr. Moses refers to four levels of denial as being the most common. We may see any or all of these levels.

- ◆ Parents may deny that the child has a disability.
- ◆ Parents may accept the diagnosis, but deny the permanence of the disability. (This is a grandparent special.)
- ◆ Parents may accept both the diagnosis and permanence but deny the impact. (This is the parent who agrees to everything, but says “so what.” They believe the impact will not change their lives.)

Parents may deny feelings. (“Yes, yes...but there is “no point in crying over spilt milk.”) It is important to remember: These are normal, helpful reactions to what you are facing.

Anxiety

When a person loses a dream that is central to their being, they are forced to make major changes within themselves and within their environment. To deal with having a child with a disability, parents go through dramatic changes that affect their attitudes, priorities, values, and beliefs, as well as altering day-to-day routines. Such changes require a great deal of energy. Anxiety mobilizes the energy needed to make these changes. Further, it gives focus to that energy so that the changes can be actualized. Anxiety is the inner source of the need to act.

Anxiety is generally seen as hysterical, inappropriate, and an unacceptable way to behave. As a rule we advise anxious people to “calm down,” to take medication, or to use alcohol as a “solution” for the “problem” of anxiety. These solutions keep the parent from changing and often make things worse for all concerned. Realities must be faced, stressful as they might be. It does not take long for most parents to become aware that they, not some professional, are their child’s medical, educational, and therapy managers, even though they may have minimal knowledge of these areas. That alone, should drive home the urgent need for energies to be mobilized and focused by the crucial feeling of anxiety.

Fear

Fear is a common reaction to the unknown. When we are told that our child's development may not be "typical" we feel apprehensive. These fears may make you anxious about the uncertain future, inadequate as a parent and unprepared to meet your child's needs. As anxiety mobilizes people to deal with change, fear is a warning that alarms the person to the seriousness of the internal changes that are demanded. One's sense of balance and order are dramatically challenged when one confronts a meaningful loss. Significant losses produce a profound sense of abandonment and vulnerability. We have a number of sayings to cope with this level of fear, e.g., "It is far better to have loved and lost, than to have never loved at all." The parents may experience the terror of knowing that they may have to make changes on a fundamental level, against their will, with full understanding that the process of internal change is very difficult. Fear is the medium that encourages the struggle to reattach, to love again in the face of a loss.

Guilt

Parents of children with a disability manifest guilt through the normal course of grieving and are sometimes criticized for doing so. Guilt is a feeling state that has become so identified with being neurotic that people feel guilty about feeling guilty. Since sharing such feelings often evokes negative judgments, it can be difficult for some parents to talk about guilt freely. On the surface, guilt-ridden people may appear not only neurotic, but superstitious, ignorant, and primitive. They are often viewed as unpleasant, uncomfortable people to be with, and therefore are dismissed or treated harshly by friends, family, and professionals.

Human beings begin to question the "why" of things from very early on in their lives. Guilt can be expressed through the parent's belief that good things happen to good people, and bad things happen to bad people. A most important "why" concerns how one's "right" or "wrong" actions affect one's life. When people confront a loss, the beliefs they held impact their life and their beliefs are deeply shaken. The order of things is totally upset when an innocent child suffers. The parent experiences deep pain that can be used to want to make things right. Guilt is the feeling state that facilitates this struggle to reorder. Basically, the guilt-ridden person is saying that they are accepting responsibility for everything. It feels better to do that than to believe that they have no influence on anything! Guilt, in this sense, helps one to redefine responsibility in light of loss.

Feelings of Depression

Many parents said they experienced depression when their child was diagnosed as having delayed development. Sadness can be triggered by the sight of another baby doing the things your baby isn't. Or, it may be tied into dreams and expectations that you had for your child's life and your own. Often depression or depressed feelings may occur unexpectedly, without you even knowing why. A common response to loss often is characterized by profound and painful sobbing. Parents report that at times it feels as though the tears will never stop. There is a rest, but then for no apparent reason, waves of despair and anguish wash over the parent once more. There may be periods of silence that may last well beyond the periods of tears. The thoughts of depression take over, thoughts like: "What's the use of trying, it's all over," or "Nothing I do matters, because nothing will change what has happened to my child!" When people display such feelings, they are often told to "cheer up," given medication, or offered distractions. Such responses are inappropriate; feeling depressed is part of normal, necessary, and growthful grieving. It attends to another aspect of a basic human struggle that loss stirs.

People use certain criteria to decide if they are OK or not. Each person determines these standards privately, even secretly. When parents have a child with a disability, usually the same standards no longer apply. How does a mother feel when she has a daughter who will not have the same accomplishments as those of her peers? The mother can't use the measures of her peers, like having a daughter graduate from college, or become homecoming queen. How does the father feel who cannot "fix" what has happened to his son with a disability? Out of this struggle of defining one's worth come the frightening feelings of helplessness, hopelessness, and haplessness. Faced with loss, a parent feels unable to act effectively (helpless), unable to imagine that things will ever get better (hopelessness), and unable to believe that their lives are touched by good luck (hapless).

Such feelings are terrifying for both the parents and those around them. For that reason, it is hard to see that the feeling of depression is a normal and necessary part of the grieving process. Depression is the medium that helps parents come to new definitions of what it takes to meet the challenges of their child, even though their child has needs that they cannot change.

When your child's health is threatened or worse yet, his life, it changes the way you look at things.

Anger

Anger, for many people, is the most disconcerting of the feeling states. It too, is a natural and necessary part of the grieving process. Parents feel anger about their child's condition and the shattering of their dreams. It is not uncommon for parents to direct their anger toward the doctor who diagnosed their infant, toward each other, toward, their child, God or close friends and family. Often, they will hear themselves saying, "it's not fair" or "life isn't fair." It is perfectly normal to feel anger at the unjustness. When one encounters a significant loss, it is likely that one's internal sense of justice is severely challenged. To continue to trust in the world, one must have a sense of justice that confirms an orderliness and fairness to the way the world works.

The angry parent may experience rejection by others, confusion about feeling anger and acting out the feeling, the feeling of being out of control. All of this makes it very difficult for this important feeling to run its course. Anger also poses other dilemmas. Unlike the other feeling states of grieving, anger is directed toward someone or something. Who (or what) is the object of parental anger? This question deeply distresses most parents, because the honest answer is often so troubling that many people avoid asking themselves the question. The unacceptable answer, of course, is that the child with the disability is the object of anger.

Most parents were raised to believe that feeling and expressing negative feelings about one's child is taboo. "The child never asked to have a disability!" "How can one be reasonably angry at this child?" If the child is blameless, then it must be unreasonable to feel anger toward the child. The conflict between what parents feel and what they can permit themselves to express can cause a return to denial. Another outcome of this conflict is that the parent can displace the anger onto others. Spouses, typical siblings of the child with a disability, and professionals are all possible targets of this displaced anger.

When considering the feeling states of grieving, especially the feeling state of anger; logic, and reason are irrelevant. Expressing anger opens the way to address the meaning of justice (though acting angry doesn't allow parents to think about what their true anger is about). While there is no logic, there is purpose and function to the expression of angry feelings. It helps them to redefine one's concepts of fairness and justice. New perceptions of themselves and their world serve as a solid foundation for coping with the disability of the child and for personal growth.

Anger is a demand for change, a passionate wish for things to be different.

Rachael Remen

Yielding to the grieving process helps parents find the inner strength and external support needed to face profound loss; to mobilize and focus the energies needed to change their lives; to find new dreams and loves. The different feeling states of denial, anxiety, fear, depression, guilt, and anger may be used in surprisingly positive ways when the feelings are fully shared.

Many parents experience the roller coaster of good and bad days.

Learning to Cope

Undoubtedly, you have felt some or all of these emotions along with many others. Acknowledging your feelings, and recognizing that other parents feel the same things will help you move toward accepting your child's diagnosis and planning for your child's new life.

It is when a parent gets "stuck" in a particular emotional state, unable to move on, that feelings become counterproductive. Most parents have developed coping strategies to help the "move through" their different emotions and get on with other things.

Emotions are healthy responses to difficult situations. Using specific coping mechanisms will help you maintain a healthy balance in your life and allow you to deal with each situation in a productive and positive way. Emotions do not magically “disappear” or go away at some point in time. Feelings recur throughout your life as you encounter new and stressful situations, make difficult transitions, or realize that your child has missed certain developmental milestones. At those times, it is important that you acknowledge your feelings, allow yourself that permission to feel that way, and reach into a well-developed repertoire of coping strategies to help you deal with the situation. Then get on with your life!

Remember

People with disabilities, parents, and other family members are each in a different stage of the grief cycle and may not be able to communicate where they are.

*This Article is Reprinted and Adapted From WAYS MAGAZINE, Spring 1987,
and the Family Information Network: Family Child Learning Center, Tallmadge, OH*

The Healthy Child

by Nicole Griffin, a Sibling's Perspective

I was four when my brother was born, and for the first five years of his life, he was a very sickly child, and who also had very significant developmental delays. Although his health eventually recovered, he always required more care and attention than a typical child. Throughout his life, every bit of progress that was made – the milestones that other families take for granted – has been a struggle. During the 22 years of his life, our family's focus has been getting him the medical, educational, and care that he has needed.

When a child of the family is very ill, the lives of everyone in the family are changed, including the lives of the other, healthy siblings. Just as the sick child is denied a typical childhood, so are his healthy brothers and sisters. The health of that child becomes the overriding concern of the entire family. When most children and teenagers just want to be like their peers, there is very little in the healthy child's family life that their peers can relate to.

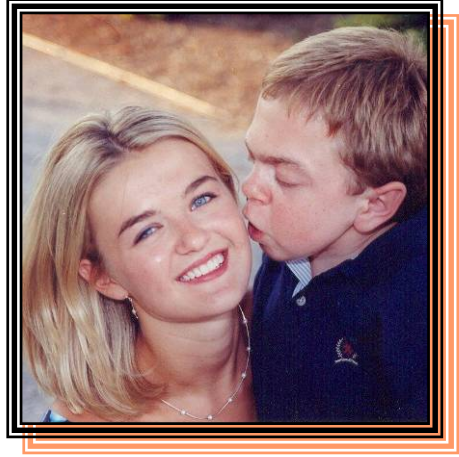
Reflecting on the years of my childhood, a few things stand out in my memory. On one hand, it surprises me now how well I handled even the most difficult times. When I was only seven years old, I saw my parents take my brother to a hospital hundreds of miles from our home, where he would undergo what would either be a life-ending or life-saving procedure. I was left behind with family, well aware that I might never see my little brother again. Although I was young, I understood what was happening, and took it all as a matter of course. Children are resilient – in some ways, family adversity is easier on the other children than it is on the parents.

On the other hand, I knew that I was missing things because my brother required so much care. I missed my parents' time (even though I never really felt neglected), which was necessarily devoted more to my brother than to myself. I missed having a "normal" sibling relationship, like my peers had with their brothers and sisters. All the silly things that brothers and sisters do to torment one another – fighting, playing pranks, running and telling Mommy on each other – were things I knew I would never have with my brother. And as soon as I was old enough, I became his caregiver, caring for him during the summer and after school. I missed out on many of the extracurricular activities that my peers enjoyed.

It was also socially difficult to deal with having a brother who was "different." For many years, I was reluctant to explain my brother to my peers, because I was embarrassed that my brother wasn't "normal" like everyone else's. At the same time, I was fiercely protective of him. When my brother first began attending my school when I was in the second grade, I vowed to myself that if anyone made fun of him because he was different, I would beat them up (a threat I fortunately never had to make good on).

Helping Siblings Cope

Now that I am an adult, I can honestly say that the adversity my family went through when I was a child made me the person I am today – strong, independent, grounded, and confident. I saw my family emerge intact from one of the most trying situations any family can go through, and it made me optimistic, motivated, and positive, not at all cynical. I would never claim to be thankful for what happened to my brother, but to some extent, I am thankful for the person I've become because of it.



Children often feel guilt, jealousy, resentment, anger, neglect, and regression surrounding their sibling's illness, hospitalization, or disability. Their lives are disrupted and routines are likely to be altered to accommodate the sick child. It is normal if your healthy child experiences some behavioral problems and regression as a result. Below are tips for helping siblings cope.

Tips for Helping Siblings Cope:

- ◆ Speak honestly – Children respond better when given honest, age appropriate information. It is far worse to protect siblings by not giving them information. When left to their own imagination, they may create a far more frightening situation than what is actually occurring.
- ◆ Maintain routine – It is important to provide siblings with as close to normal a routine as possible. Allow family and friends to assist you in maintaining a daily routine at home.
- ◆ Encourage communication
- ◆ *Talk* – Children need to know it's okay to ask questions and express feelings.
- ◆ *Play* – Children learn and discover their work through play. It is also a way for children to express feelings when they are unable to express with words.
- ◆ Help siblings handle common reactions
- ◆ *Jealousy* – Children may feel it's unfair that they are getting less attention. Here are some ways to help. Make special time for your well child. Provide special gifts or appreciation for helping. Have someone special, a family member or a friend, be available to them at times when you cannot be present.
- ◆ *Fear* – They may feel insecure that something may happen to them or that they can catch the illness. Allow them to express their feelings.
- ◆ *Guilt* – Children may feel that something they said or did caused their brother or sister to be in the hospital. Reassure them that their feelings are normal and they are not responsible.
- ◆ *Sadness* – It is normal to feel an overwhelming sadness. During the time you spend away from home, provide a special reminder of you, some comfort items.
- ◆ Encourage siblings to visit the hospitalized child (if possible) – Provide age appropriate explanations about the sibling, allowing your child to understand at her or his level.
- ◆ Prepare the sibling for a hospital visit – It's best if they know what to expect. A photograph may be helpful, so they won't be alarmed or frightened.
- ◆ Alert teachers, coaches, and leaders of siblings about the changes and stresses at home – This will foster support for the sibling academically as well as emotionally.
- ◆ Enroll the sibling in support groups – It is important for them to be involved, identify with others, and create friendships with those going through similar stresses.

Medically Fragile Case Management Program

Family Handbook Acknowledgement

The Medically Fragile Case Management Program Family Handbook has been developed for your information and as a resource for understanding the policies, forms, benefits, and services available regarding the Medically Fragile Case Management Program. Please review it carefully. This signed copy will be filed in the recipient’s chart.

This handbook is not intended to cover every situation which may arise; it is simply an informational guide to the Medically Fragile Case Management Program’s role and responsibilities. We are hopeful that it will be a useful reference for you now, and in the future.



I have received a copy of the Medically Fragile Case Management Program Family Handbook, which outlines the goals, policies, benefits, and expectations of the Medically Fragile Case Management Program.

Recipient’s Signature: _____

Family Signature: _____

Printed Name: _____

Client’s Name: _____

Date: _____