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
Lynn Griffin
Family Specialist, MFCMP

edited by
Julie Bachechi
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.
# Table of Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 1 – The Medically Fragile Case Management Program</td>
<td>I-1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What is The Medically Fragile Waiver?</td>
<td>I-2</td>
</tr>
<tr>
<td></td>
<td>What is the Definition of Medically Fragile?</td>
<td>I-2</td>
</tr>
<tr>
<td></td>
<td>Eligibility</td>
<td>I-2</td>
</tr>
<tr>
<td></td>
<td>Financial</td>
<td>I-3</td>
</tr>
<tr>
<td></td>
<td>Medical</td>
<td>I-3</td>
</tr>
<tr>
<td></td>
<td>What is the Definition of a Developmental Disability?</td>
<td>I-3</td>
</tr>
<tr>
<td></td>
<td>What Service Options Are Offered Through the Medically Fragile Waiver</td>
<td>I-4</td>
</tr>
<tr>
<td></td>
<td>Program?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Allocation - Level of Care</td>
<td>I-5</td>
</tr>
<tr>
<td></td>
<td>What is an Individualized Service Plan?</td>
<td>I-6</td>
</tr>
<tr>
<td></td>
<td>What is the Role of Your Case Manager During This Process</td>
<td>I-6</td>
</tr>
<tr>
<td>Chapter 2 – What is the Early Periodic Screening, Diagnosis, and</td>
<td>I-8</td>
<td></td>
</tr>
<tr>
<td>Treatment (EPSDT)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>What is the Role of Nursing Agencies and Various Other Agencies</td>
<td>I-9</td>
</tr>
<tr>
<td></td>
<td>What Services Might be Available Through Home HealthCare</td>
<td>I-10</td>
</tr>
<tr>
<td></td>
<td>Services Not Allowed</td>
<td>I-10</td>
</tr>
<tr>
<td>Chapter 3 – What is Social Security Supplemental Income (SSI), and</td>
<td>I-11</td>
<td></td>
</tr>
<tr>
<td>How Do I Apply</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>What is the Family Infant Toddler Program (FIT)?</td>
<td>I-12</td>
</tr>
<tr>
<td></td>
<td>What is Early Intervention (EI)?</td>
<td>I-12</td>
</tr>
</tbody>
</table>
Where May Services Be Provided? ................................................................. I-12
Sample Individualized Family Service Plan (IFSP) Agenda ............................. I-13
Getting Ready for Your ISP - Notes Page ....................................................... I-13
Individualized Service Plan (Blank Forms) ..................................................... I-14

**Chapter 4 – Other Waiver Programs Available in New Mexico ................. I-26**

The Developmental Disabilities (DD) Home and Community-Based Waiver ................................................................. I-26
Service Options Offered Through the Developmental Disabilities Waiver Program ................................................................................. I-26

The Disabled and Elderly (D&E) Waiver Program ........................................ I-27
Service Options Offered Through the Disabled & Elderly Waiver Program ........ I-27

Mi Via - Self Directed Waiver Services ......................................................... I-28

The AIDS Waiver ............................................................................................. I-28

**Chapter 5 – Resources ................................................................................ I-29**

Welcome to the World of Acronyms ............................................................. I-37
Support Groups/Community Resources ......................................................... I-41

New Mexico Income Support Division Offices by County ............................. I-45
<table>
<thead>
<tr>
<th>Section II – Care Notebook</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>◇ Emergency Medical Information Form for Children With Special Needs</td>
<td>II-2</td>
</tr>
<tr>
<td>◇ My Child’s Profile - Medical Record</td>
<td>II-3</td>
</tr>
<tr>
<td>◦ Personal Information – Family/Care Providers Emergency Contacts</td>
<td>II-3</td>
</tr>
<tr>
<td>◦ Primary Care Provider</td>
<td>II-3</td>
</tr>
<tr>
<td>◦ Primary and Secondary Diagnosis – Medical Alerts – Insurance Information</td>
<td>II-4</td>
</tr>
<tr>
<td>◦ Surgeries or Procedures – Hospital Admissions</td>
<td>II-5</td>
</tr>
<tr>
<td>◦ Respiratory Care</td>
<td>II-6</td>
</tr>
<tr>
<td>◦ Current Status of Sensory and Ability Information</td>
<td>II-6</td>
</tr>
<tr>
<td>◦ Vision</td>
<td>II-6</td>
</tr>
<tr>
<td>◦ Hearing</td>
<td>II-6</td>
</tr>
<tr>
<td>◦ Mobility/Orthotics</td>
<td>II-7</td>
</tr>
<tr>
<td>◦ Communication</td>
<td>II-7</td>
</tr>
<tr>
<td>◦ Developmental Screening</td>
<td>II-7</td>
</tr>
<tr>
<td>◦ Monthly Weight Chart</td>
<td>II-9</td>
</tr>
<tr>
<td>◇ Tips on Preparing to See the Doctor</td>
<td>II-10</td>
</tr>
<tr>
<td>◇ Notes From Doctor Appointments</td>
<td>II-11</td>
</tr>
<tr>
<td>◇ Appointment Log</td>
<td>II-12</td>
</tr>
<tr>
<td>◇ Question’s to Ask the HMOs: A Parent’s Guide</td>
<td>II-13</td>
</tr>
<tr>
<td>◇ Describe a Typical Day for Your Child</td>
<td>II-15</td>
</tr>
<tr>
<td>◇ Care Schedule</td>
<td>II-19</td>
</tr>
<tr>
<td>◇ Seizure/Behavior Log</td>
<td>II-21</td>
</tr>
<tr>
<td>◇ Medication Log</td>
<td>II-22</td>
</tr>
<tr>
<td>◇ Monthly Supply Log</td>
<td>II-23</td>
</tr>
<tr>
<td>◇ Monthly Consumable Supplies</td>
<td>II-24</td>
</tr>
<tr>
<td>◇ School Information</td>
<td>II-26</td>
</tr>
<tr>
<td>◇ Transitions – Looking Ahead</td>
<td>II-27</td>
</tr>
<tr>
<td>Topic</td>
<td>Page</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Future Estate Planning</td>
<td>II-29</td>
</tr>
<tr>
<td>Estate Planning Worksheets</td>
<td>II-30</td>
</tr>
<tr>
<td>Guardianship in New Mexico for People With Disabilities</td>
<td>II-34</td>
</tr>
<tr>
<td>Important Terms</td>
<td>II-35</td>
</tr>
<tr>
<td>Resources</td>
<td>II-38</td>
</tr>
<tr>
<td>Strategies for Managing Life</td>
<td>II-40</td>
</tr>
<tr>
<td>Communication - Messages We Give and Get</td>
<td>II-53</td>
</tr>
<tr>
<td>Communication Log</td>
<td>II-55</td>
</tr>
<tr>
<td>Taking Care of Yourself</td>
<td>II-57</td>
</tr>
<tr>
<td>The Power to Choose - Building Family Strengths</td>
<td>II-58</td>
</tr>
<tr>
<td>The Parent’s Struggle, Pain, and Healing</td>
<td>II-60</td>
</tr>
<tr>
<td>The Feeling States of Grieving</td>
<td>II-61</td>
</tr>
<tr>
<td>The Healthy Child</td>
<td>II-66</td>
</tr>
<tr>
<td>Helping Siblings Cope</td>
<td>II-67</td>
</tr>
<tr>
<td>Family Handbook Acknowledgement</td>
<td>II-68</td>
</tr>
</tbody>
</table>
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.

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 has 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.
Section I

Family Handbook
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/EPSDT (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 three Salud! programs – Molina, Presbyterian Salud!, and Lovelace Community Health Plan, 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 EPSDT; 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 DDSD 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-14) |

**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
♦ 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.

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 is on page I-14 for you to familiarize yourself to the plan process.

**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.
- 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.

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

*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.*
♦ 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.
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

**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 three Saluds! – Molina, Presbyterian, and Lovelace 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.
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.

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

WHERE MAY SERVICES BE PROVIDED?

Services are generally provided in places that would be considered natural environments for any child without a disability or a medical condition. This would be where your child typically lives, learns, and plays which may include your home, a childcare setting, recreation center, or other community settings.

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.
SAMPLE INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP) AGENDA

A. Introductions
B. Purpose and outcomes of meeting
C. Review agenda
D. State ground rules and review assessment results
E. Who is “Betsy Jones?”
F. Have the child/family tell first who they are, likes, preference, etc.
G. Live, work/learn, have fun/develop relationships
H. Objectives and strategies due within 10 working days after meeting (FIT only)
I. Budget/services, discussion, and summarize (who, what)

If you have a child who qualifies for Early Intervention (EI) services and Medically Fragile services, the IFSP would be developed to incorporate any programs to work together and compliment one another.

Notes Page
Getting Ready for Your ISP

The following blank ISP form 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.
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 El Recipient)

Date of Birth/Age: ___________    Adjusted Age: ___________

Address: ____________________________________________

_________________________________________________________________

Telephone Number: ____________________________________________

MFCMP ID NO.: ____________________________________________

Insurance Coverage: ____________________________________________

Salud! Provider: ____________________________________________

Family Members: ____________________________________________

Primary Language: ____________________________________________
TEAM MEMBERS:

<table>
<thead>
<tr>
<th>Name</th>
<th>Duration / Frequency</th>
<th>Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PRENATAL HISTORY:

_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
_____________________________________________________________

HEALTH HISTORY / CURRENT STATUS:

_____________________________________________________________
_____________________________________________________________
_____________________________________________________________

MEDICAL FRAGILITY ASSESSMENT FACTORS:

1. MEDICATION ADMINISTRATION: _____________________________
2. MEDICAL CARE/SUPERVISION: _____________________________
3. NUTRITIONAL STATUS/FEEDING: ___________________________
   - Ability to Eat/Swallow: _______________________________
   - Skilled Intervention: _________________________________
4. RESPIRATORY STATUS: _________________________________
5. NEUROLOGICAL: _____________________________
6. SLEEP PATTERN: _________________________________
7. HEIGHT: _______ WEIGHT: _______ BMI: _______
8. ALLERGIES: __________________________________________

9. IMMUNIZATIONS: ______________________________________

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

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

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

Psychosocial Counseling:

Nutritional Counseling:

Medical Supply Company:

School:

Early Childhood Intervention – Birth to Three Years (see the forms to use on the next two pages):

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.
**Supports and Services Needed to Achieve Outcomes**

This is a summary of the decisions made by the Interdisciplinary Team (IDT) regarding supports and services needed to achieve all outcomes. The method of service delivery is documented on each outcome page (see FIT Family Handbook for information on all available early intervention services).

<table>
<thead>
<tr>
<th>ISP Supports &amp; Services</th>
<th>To Help With Outcomes</th>
<th>*Setting (see codes below)</th>
<th>Frequency (i.e., 1X, 2X)</th>
<th>Period (day/week/month/quarter/year)</th>
<th>Intensity (# of minutes)</th>
<th>Provider (Name of Agency)</th>
<th><strong>Funding Source (see codes below)</strong></th>
<th>Start Date</th>
<th>End Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Primary location of service (more than 50% of services occur here):____________________

**Setting Codes:**
H = Home as primary service setting (may occasionally go into community)
DD = Program designed for children with developmental delays or disabilities
TD = Program designed for typically developing children (include child care, Early Head Start, etc.)
HOS = Hospital (inpatient)
RF = Residential Facility
SPL = Service Provider Location (Not EI office, Mayo Clinic, hospital, etc.)
O = Other setting in community (park, restaurant, recreation center, etc.)

**Funding Source Codes:**
M = Medicaid (fee-for-service)
SGF = State General Funds
M(S) = Medicaid (Salud!)
I = Private Insurance
C = Community Resource
PP = Parent Pay – sliding fee scale
CMS = Children’s Medical Services
O = Other
Outcome #______
What we want to see for our child/family as a result of early intervention supports and services.

What will progress look like?

Our Strategies:
Who will do what in which everyday routines, activities, and places?

Supports and services must be provided to your child in settings that are natural or typical for children of the same age (natural environments). If, as a team, we decide that we cannot achieve an outcome in a natural environment, we need to describe how we made that decision, and what we will do to move services and supports to natural environments as soon as possible.

This outcome cannot be achieved by providing supports and services in natural environments because:

We will work toward providing supports and services in natural environments to achieve this outcome by (describe plan and timeline):
### EQUIPMENT & SUPPLIES

<table>
<thead>
<tr>
<th>Article</th>
<th>Source</th>
<th>Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### MEDICATIONS

<table>
<thead>
<tr>
<th>Name</th>
<th>Dosage</th>
<th>Frequency</th>
<th>Route</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
STATEMENT OF RECIPIENT / FAMILY RIGHTS AND RESPONSIBILITIES

As a recipient/family receiving services through the Medically Fragile Case Management Program (MFCMP), you have certain rights and responsibilities. The following information was compiled for your convenience in exercising your rights and understanding your responsibilities.

RECIPIENT / FAMILY RIGHTS:

♦ All recipients/families have a right to be fully informed of services available to them and are requested to participate in the development of the Individualized Service Plan (ISP).

♦ All recipients/families have the right to choose providers and case management agencies when alternative providers are available. Once services have begun, service providers may be changed, if needed.

♦ All recipients/families have a right to confidentiality. There will not be a release of medical, psychological, or therapeutic information to persons not involved in your care, without your consent.

♦ All recipients/families have a right to be free from mental or physical abuse and discrimination based on race, color, creed, sex, age, disability, or sexual orientation.

♦ All recipients have a right to 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.

♦ All recipients have a right to prompt attention.

♦ All recipients/families have a right to refuse Medically Fragile Waiver or Medically Fragile EPSDT services at any time; however, failure to use services may jeopardize further provision of services.
♦ All recipients/families have a right to appeal any decision made regarding eligibility, service delivery, and termination of services.

♦ Concern about any of these matters should be raised to the recipient’s case manager. It is most desirable to resolve the problem with your case manager.

♦ If the recipient/family does not feel the problem has been resolved, it needs to be raised to the immediate supervisor for the case manager at the Medically Fragile Case Management Program. The supervisor can be reached at the telephone number listed above. The supervisor has information on the grievance process if needed.

♦ Should the recipient/family still feel that the problem has not been adequately resolved, the next step is to contact the Program Manager at Developmental Disabilities Supports Division/Department of Health for recipients receiving services through the Medically Fragile Waiver.

♦ For recipients receiving services through the Medically Fragile Salud! Program, each Salud! program has a specific grievance process. The recipient/family can contact their Salud! program through the toll free member services number. (See your Salud! member card for these toll free numbers.)

♦ For recipients on Medicaid that are classified as Fee-for-Service (Exempt from Salud!), the grievance is submitted to the Program Manager at the Medical Assistance Division/Benefits Bureau in Santa Fe.

♦ Case Management has the contact numbers and process information for all programs.

♦ Response to any matter of concern shall be no more than five (5) working days after the initial presentation of the issue. All such matters shall be treated with confidentiality.

Concern about any of these issues should be raised to the recipient/family’s Case Manager or to the Program Director of the Medically Fragile Case Management Program.

**RECIPIENT / FAMILY RESPONSIBILITIES:**

♦ To show consideration, courtesy, and respect to all persons involved with your care or your child’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.

♦ Services and supports are not replacements for the family system, 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.
To cooperate with your Case Manager, physician, provider agencies, and your ISP.

To obtain necessary information (such as income verification, medical information) in order to process your application for services.

Notify the Income Support Division (ISD) office of any change of status, such as address, name, or income changes.

To be available to meet with the Case Manager at a face-to-face visit every other month, and by telephone on the months the face-to-face visits aren’t held, or to notify the Case Manager if unable to do so.

Complete and sign the Third Party Liability (private insurance) Information Form.

To notify your Case Manager regarding any of the following:
- Hospitalization
- Changes in income, insurance, finances
- Changes in scheduled hours of services, such as nursing or therapies
- Request usage of respite (reasonable notice shall be given with requests)
- Any periods of time in which scheduled services will not be used
- Change in address, telephone number or living arrangements
- Changes of physicians, therapists, medical suppliers
- Any services being received from another in-home agency

Failure to comply with these responsibilities may result in closure of your case per Medicaid and Department of Health Policies and Procedures, Section V.

RN / CASE MANAGER’S ROLE AND RESPONSIBILITIES:

To assist and support individuals who are medically fragile and their families.

Identify and assist in accessing the supports and services needed for the recipient to live at home.

To develop the ISP based on the needs identified by the recipient/family and the Interdisciplinary Team (IDT). The IDT consists of physicians, service providers, and schools.

Coordinate services through the MFCMP including nursing, therapies, durable medical equipment and supplies, and other needs as identified by the family and the healthcare team.

To link individuals and their families to natural supports and direct service providers.

To monitor the delivery of these services as specified in the individual’s ISP.
Maintain regular communication with the recipient/family and the service providers and members of the IDT.

- To make a minimum of every other month face-to-face visit.
- To be available to recipients/families, returning messages within one working day.
- Re-evaluate the ISP on an ongoing basis, making revisions as necessary.
- Coordinate a formal re-evaluation in 6 months with the entire IDT, if indicated.
- Annually reassess eligibility for services and complete necessary paperwork.
- Report any known or suspected incidents of abuse, neglect, and/or exploitation.
- 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 Medically Fragile Case Management Program, CDD, UNM Health Sciences Center. I have also read the MFCMP Case Manager’s role and responsibilities.

If recipient is a minor:

<table>
<thead>
<tr>
<th>Signature of Parent or Guardian</th>
<th>Relationship to Recipient</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>_______________________________</td>
<td>__________________________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature of Recipient</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>______________________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature of Case Manager</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>_________________________</td>
<td></td>
</tr>
</tbody>
</table>
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
THE DISABLED AND ELDERLY (D&E) WAIVER PROGRAM

The Disabled and Elderly Waiver Program is a home and community-based waiver designed to provide services to the disabled and elderly in their homes.

- 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 THE DISABLED & ELDERLY WAIVER PROGRAM

- Case Management
- Adult Day Health
- Assisted Living
- Emergency Response Services
- Environmental Modification
- Homemaker Services for Adults

Contact Aging and Long-Term Services Division (ALTSD) Resource Center at (800)-432-2080 for more information.
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. Waiver recipients who receive services through waiver programs, such as the Disabled and Elderly (D&E), 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.
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 look 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).
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.

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAC</td>
<td>Augmentative and Alternative Communication</td>
</tr>
<tr>
<td>AAMR</td>
<td>American Association on Mental Retardation</td>
</tr>
<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
</tr>
<tr>
<td>ABS</td>
<td>Adaptive Behavior Scale</td>
</tr>
<tr>
<td>ADA</td>
<td>Americans with Disabilities Act</td>
</tr>
<tr>
<td>ADD</td>
<td>Attention Deficit Disorder</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>AG</td>
<td>State Attorney General’s Office</td>
</tr>
<tr>
<td>AL</td>
<td>Assisted Living</td>
</tr>
<tr>
<td>AIMS</td>
<td>Abnormal Involuntary Movements Screening</td>
</tr>
<tr>
<td>APE</td>
<td>Adapted Physical Education</td>
</tr>
<tr>
<td>APS</td>
<td>Adult Protective Services or Albuquerque Public Schools</td>
</tr>
<tr>
<td>ARA</td>
<td>Annual Resource Allotment</td>
</tr>
<tr>
<td>ARCA</td>
<td>Association for Retarded Citizens of Albuquerque</td>
</tr>
<tr>
<td>Arc of NM</td>
<td>State Advocacy Agency—Association of Retarded Citizens</td>
</tr>
<tr>
<td>ASA</td>
<td>Autism Society of America</td>
</tr>
<tr>
<td>ASL</td>
<td>American Sign Language</td>
</tr>
<tr>
<td>AT</td>
<td>Assistive Technology</td>
</tr>
<tr>
<td>BBS</td>
<td>Bureau of Blind Services</td>
</tr>
<tr>
<td>BC/BS</td>
<td>Blue Cross/Blue Shield</td>
</tr>
<tr>
<td>BD</td>
<td>Behavior Disorder</td>
</tr>
<tr>
<td>BIA</td>
<td>Bureau of Indian Affairs</td>
</tr>
<tr>
<td>BID</td>
<td>Twice a Day</td>
</tr>
<tr>
<td>BIP</td>
<td>Behavior Intervention Plan</td>
</tr>
<tr>
<td>BMS</td>
<td>Behavior Management Specialist</td>
</tr>
<tr>
<td>BSP</td>
<td>Behavior Support Plan</td>
</tr>
<tr>
<td>BT</td>
<td>Behavior Therapy or Therapist</td>
</tr>
<tr>
<td>CARF</td>
<td>Commission on the Accreditation of Rehabilitation Facilities</td>
</tr>
<tr>
<td>CDD</td>
<td>Center for Development &amp; Disability</td>
</tr>
<tr>
<td>CEC</td>
<td>Council for Exceptional Children</td>
</tr>
<tr>
<td>CF</td>
<td>Cystic Fibrosis</td>
</tr>
<tr>
<td>CM</td>
<td>Case Manager</td>
</tr>
<tr>
<td>CMA</td>
<td>Certified Medication Aide or Case Management Assessment</td>
</tr>
<tr>
<td>CMS</td>
<td>Children’s Medical Services or Center for Medicare and Medicaid Services (formerly HCFA: Healthcare Financing Authority)</td>
</tr>
<tr>
<td>COC</td>
<td>Continuum of Care Program</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>CPR</td>
<td>Cardiopulmonary Resuscitation</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>CPS</td>
<td>Children’s Protective Services</td>
</tr>
<tr>
<td>CYFD</td>
<td>Children, Youth and Families Department</td>
</tr>
<tr>
<td>DD</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>D and E</td>
<td>Disabled and Elderly Waiver</td>
</tr>
<tr>
<td>DDPC</td>
<td>Developmental Disabilities Planning Council</td>
</tr>
<tr>
<td>DDSD/DOH</td>
<td>Developmental Disabilities Support Division, Department of Health</td>
</tr>
<tr>
<td>DDW</td>
<td>Developmental Disability Waiver</td>
</tr>
<tr>
<td>DH</td>
<td>Day Habilitation</td>
</tr>
<tr>
<td>DHH</td>
<td>Deaf and Hard of Hearing</td>
</tr>
<tr>
<td>DME</td>
<td>Durable Medical Equipment</td>
</tr>
<tr>
<td>DOE</td>
<td>Department of Education</td>
</tr>
<tr>
<td>DOH</td>
<td>NM Department of Health</td>
</tr>
<tr>
<td>DRP</td>
<td>Dispute Resolution Process</td>
</tr>
<tr>
<td>DSS</td>
<td>Direct Support Staff</td>
</tr>
<tr>
<td>Dx</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>DVR</td>
<td>Division of Vocational Rehabilitation, Department of Education</td>
</tr>
<tr>
<td>EA</td>
<td>Education Assistant</td>
</tr>
<tr>
<td>ECG/EKG</td>
<td>Electrocardiogram</td>
</tr>
<tr>
<td>ED</td>
<td>Emotional Disturbance</td>
</tr>
<tr>
<td>EI</td>
<td>Early Intervention</td>
</tr>
<tr>
<td>EEG</td>
<td>Electroencephalogram</td>
</tr>
<tr>
<td>EPSDT</td>
<td>Early Periodic Screening, Diagnosis, and Treatment</td>
</tr>
<tr>
<td>ESL</td>
<td>English Second Language</td>
</tr>
<tr>
<td>ESY</td>
<td>Extended School Year</td>
</tr>
<tr>
<td>FAPE</td>
<td>Free and Appropriate Education</td>
</tr>
<tr>
<td>FERPA</td>
<td>Family Educational Rights and Privacy Act</td>
</tr>
<tr>
<td>FAS</td>
<td>Fetal Alcohol Syndrome</td>
</tr>
<tr>
<td>FBA</td>
<td>Functional Behavior Assessment</td>
</tr>
<tr>
<td>FCR</td>
<td>Family-Centered Review</td>
</tr>
<tr>
<td>FFS</td>
<td>Fee-for-Service</td>
</tr>
<tr>
<td>FIT</td>
<td>Family Infant Toddler Program</td>
</tr>
<tr>
<td>FOC</td>
<td>Freedom of Choice</td>
</tr>
<tr>
<td>FSA</td>
<td>Functional Supports Assessment</td>
</tr>
<tr>
<td>FTF</td>
<td>Face-to-Face</td>
</tr>
<tr>
<td>FYI</td>
<td>Family Youth Inc., or For Your Information</td>
</tr>
<tr>
<td>GERD</td>
<td>Gastro-Esophageal Reflux Disorder</td>
</tr>
<tr>
<td>GTT/GERD</td>
<td>Gastrostomy Tube/Gastro-Esophageal Reflux Disorder</td>
</tr>
<tr>
<td>GTT</td>
<td>Gastrostomy Tube</td>
</tr>
<tr>
<td>HI</td>
<td>Hearing Impaired</td>
</tr>
<tr>
<td>HIPAA</td>
<td>Health Insurance Portability &amp; Accountability Act</td>
</tr>
<tr>
<td>HMO</td>
<td>Health Maintenance Organization</td>
</tr>
<tr>
<td>HSD</td>
<td>Human Services Department</td>
</tr>
<tr>
<td>HUD</td>
<td>Department of Housing and Urban Development</td>
</tr>
<tr>
<td>ICAP</td>
<td>Inventory for Client and Agency Planning</td>
</tr>
<tr>
<td>ICC</td>
<td>Interagency Coordinating Council (Early Intervention Services)</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>ICF</td>
<td>Intermediate Care Facility</td>
</tr>
<tr>
<td>ICP</td>
<td>Indian Children’s Program</td>
</tr>
<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>IDT</td>
<td>Interdisciplinary Team</td>
</tr>
<tr>
<td>IEE</td>
<td>Individual Education Evaluation</td>
</tr>
<tr>
<td>IEP</td>
<td>Individualized Education Plan</td>
</tr>
<tr>
<td>IFSP</td>
<td>Individualized Family Service Plan</td>
</tr>
<tr>
<td>IHP</td>
<td>Individualized Health Plan</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
</tr>
<tr>
<td>IR</td>
<td>Incident Report</td>
</tr>
<tr>
<td>I&amp;R</td>
<td>Information and Referral</td>
</tr>
<tr>
<td>ISD</td>
<td>Income Support Division of the NM Human Services Department</td>
</tr>
<tr>
<td>ISP</td>
<td>Individualized Service Plan (for Waiver Services)</td>
</tr>
<tr>
<td>ITP</td>
<td>Individualized Transition Plan</td>
</tr>
<tr>
<td>LD</td>
<td>Learning Disability</td>
</tr>
<tr>
<td>LEP</td>
<td>Limited English Proficient</td>
</tr>
<tr>
<td>LINC</td>
<td>Library and Information Network for the Community</td>
</tr>
<tr>
<td>LPN</td>
<td>Licensed Practical Nurse</td>
</tr>
<tr>
<td>LOC</td>
<td>Level of Care</td>
</tr>
<tr>
<td>LRE</td>
<td>Least Restrictive Environment</td>
</tr>
<tr>
<td>MAD</td>
<td>Medical Assistance Division of the Human Services Department</td>
</tr>
<tr>
<td>MANDT</td>
<td>Positive Support Intervention System</td>
</tr>
<tr>
<td>MAR</td>
<td>Medication Administration Record</td>
</tr>
<tr>
<td>MAW</td>
<td>Medical Assistance Worker</td>
</tr>
<tr>
<td>MCO</td>
<td>Managed Care Organization</td>
</tr>
<tr>
<td>MD</td>
<td>Multiple Disabilities or Muscular Dystrophy or Medical Doctor</td>
</tr>
<tr>
<td>MFCMP</td>
<td>Medically Fragile Case Management Program</td>
</tr>
<tr>
<td>MFW</td>
<td>Medically Fragile Waiver</td>
</tr>
<tr>
<td>MR</td>
<td>Mental Retardation</td>
</tr>
<tr>
<td>MTP</td>
<td>Mealtime Plan</td>
</tr>
<tr>
<td>NC</td>
<td>Nutritional Counseling</td>
</tr>
<tr>
<td>NERO</td>
<td>Mental Health</td>
</tr>
<tr>
<td>NMMUR</td>
<td>New Mexico Medicaid Utilization Review</td>
</tr>
<tr>
<td>NPO</td>
<td>Nothing by Mouth</td>
</tr>
<tr>
<td>OCD</td>
<td>Obsessive Compulsive Disorder</td>
</tr>
<tr>
<td>OCR</td>
<td>Office of Civil Rights</td>
</tr>
<tr>
<td>OHI</td>
<td>Other Health Impaired</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapy</td>
</tr>
<tr>
<td>P&amp;A</td>
<td>Protection and Advocacy</td>
</tr>
<tr>
<td>PBDC</td>
<td>Parents for Behaviorally Different Children</td>
</tr>
<tr>
<td>PC</td>
<td>Personal Care</td>
</tr>
<tr>
<td>PCO</td>
<td>Personal Care Option — for individuals over the age of 21 years who are Medicaid eligible</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Physician</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------</td>
</tr>
<tr>
<td>PCS</td>
<td>Personal Care Services (approximately 3 years to 21 years through Medicaid/Saluds! — after 21 years, it is called PCO)</td>
</tr>
<tr>
<td>PDD</td>
<td>Pervasive Development Disorder</td>
</tr>
<tr>
<td>PDN</td>
<td>Private Duty Nurse—RN or LPN</td>
</tr>
<tr>
<td>PED</td>
<td>Public Education Department</td>
</tr>
<tr>
<td>PLP</td>
<td>Present Levels of Performance</td>
</tr>
<tr>
<td>PO</td>
<td>By Mouth</td>
</tr>
<tr>
<td>PRN</td>
<td>As Needed</td>
</tr>
<tr>
<td>PRO</td>
<td>Parents Reaching Out</td>
</tr>
<tr>
<td>PSD</td>
<td>Personal and Social Development</td>
</tr>
<tr>
<td>PT</td>
<td>Physical Therapy</td>
</tr>
<tr>
<td>RN</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>RO</td>
<td>Regional Office</td>
</tr>
<tr>
<td>ROM</td>
<td>Range of Motion</td>
</tr>
<tr>
<td>RX</td>
<td>Prescription</td>
</tr>
<tr>
<td>QA</td>
<td>Quality Assurance</td>
</tr>
<tr>
<td>QD</td>
<td>Every Day</td>
</tr>
<tr>
<td>QID</td>
<td>Four Times a Day</td>
</tr>
<tr>
<td>SCHIP</td>
<td>State Children’s Health Insurance Program</td>
</tr>
<tr>
<td>SE</td>
<td>Supported Employment</td>
</tr>
<tr>
<td>SGF</td>
<td>State General Fund</td>
</tr>
<tr>
<td>SI</td>
<td>Sensory Integration Treatments</td>
</tr>
<tr>
<td>SID</td>
<td>Sensory Integration Disorder</td>
</tr>
<tr>
<td>SIB</td>
<td>Self-Injurious Behavior</td>
</tr>
<tr>
<td>SL</td>
<td>Supported Living</td>
</tr>
<tr>
<td>SLD</td>
<td>Specific Learning Disability</td>
</tr>
<tr>
<td>SLT/SLP</td>
<td>Speech-Language Therapy/Speech-Language Pathologist</td>
</tr>
<tr>
<td>SS</td>
<td>Social Security</td>
</tr>
<tr>
<td>SSA</td>
<td>Social Security Administration</td>
</tr>
<tr>
<td>SSDI</td>
<td>Social Security Disability Insurance</td>
</tr>
<tr>
<td>SSI</td>
<td>Supplemental Social Security Income</td>
</tr>
<tr>
<td>ST</td>
<td>Speech Therapy or Therapist</td>
</tr>
<tr>
<td>TA</td>
<td>Technical Assistance</td>
</tr>
<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
</tr>
<tr>
<td>TDD</td>
<td>Telecommunication Devices for the Deaf</td>
</tr>
<tr>
<td>TID</td>
<td>Three Times a Day</td>
</tr>
<tr>
<td>UH</td>
<td>University Hospital</td>
</tr>
<tr>
<td>UNM</td>
<td>University of New Mexico</td>
</tr>
<tr>
<td>UNMH</td>
<td>University of New Mexico Hospital</td>
</tr>
<tr>
<td>UR</td>
<td>Utilization Review</td>
</tr>
<tr>
<td>URI</td>
<td>Upper Respiratory Infection</td>
</tr>
<tr>
<td>VI</td>
<td>Visual Impairment</td>
</tr>
<tr>
<td>VR</td>
<td>Vocational Rehabilitation</td>
</tr>
<tr>
<td>VOC</td>
<td>Vocational</td>
</tr>
<tr>
<td>WAIS-R</td>
<td>Wechsler Adult Intelligence Scale</td>
</tr>
</tbody>
</table>
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) 272-1861. 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.mpssociety.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) 273-7232; 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.ntsa.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

<table>
<thead>
<tr>
<th>County</th>
<th>Address</th>
<th>City</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bernalillo - Northeast part of Albuquerque</td>
<td>4330 Cutler NE</td>
<td>Albuquerque, NM 87125</td>
<td>222-9200</td>
</tr>
<tr>
<td>Bernalillo - Northwest part of Albuquerque</td>
<td>1041 Lamberton NE</td>
<td>Albuquerque, NM 87125</td>
<td>841-7700</td>
</tr>
<tr>
<td>Bernalillo - Southeast part of Albuquerque</td>
<td>1711 Randolph Rd. SE</td>
<td>Albuquerque, NM 87102</td>
<td>383-2600</td>
</tr>
<tr>
<td>Bernalillo - Southwest part of Albuquerque</td>
<td>1401 Old Coors Rd, SW</td>
<td>Albuquerque, NM 87195</td>
<td>841-2300</td>
</tr>
<tr>
<td>Catron</td>
<td>302 Park Avenue, SW</td>
<td>Socorro, NM 87801</td>
<td>835-0343</td>
</tr>
<tr>
<td>Chaves</td>
<td>1701 S. Sunset</td>
<td>Roswell, NM 88203</td>
<td>635-3000</td>
</tr>
<tr>
<td>Cibola</td>
<td>900 Mount Taylor Ave.</td>
<td>Grants, NM 87020</td>
<td>267-8836</td>
</tr>
<tr>
<td>Colfax</td>
<td>1900 Hospital Drive, Suite A</td>
<td>Raton, NM 87740</td>
<td>445-2308</td>
</tr>
<tr>
<td>Curry</td>
<td>1621 Sutter Place</td>
<td>Clovis, NM 88101</td>
<td>762-4751</td>
</tr>
<tr>
<td>De Baca</td>
<td>200 Lake Drive</td>
<td>Santa Rosa, NM 88435</td>
<td>472-3459</td>
</tr>
<tr>
<td>Dona Ana (Las Cruces/East Side Area)</td>
<td>2121 Summit Court</td>
<td>Las Cruces, NM 88011</td>
<td>524-6568</td>
</tr>
<tr>
<td>Dona Ana (Las Cruces/West Side Area)</td>
<td>655 Utah</td>
<td>Las Cruces, NM 88001</td>
<td>524-6500</td>
</tr>
<tr>
<td>Dona Ana (Las Cruces/Anthony Area)</td>
<td>220 Crossett Lane</td>
<td>Anthony, NM 88021</td>
<td>882-5781</td>
</tr>
<tr>
<td>Eddy</td>
<td>108 N. 16th</td>
<td>Artesia, NM 88210</td>
<td>748-3361</td>
</tr>
<tr>
<td>Grant</td>
<td>1422 Highway 180 East</td>
<td>Silver City, NM 88061</td>
<td>538-2948</td>
</tr>
<tr>
<td>Guadalupe</td>
<td>200 Lake Drive</td>
<td>Santa Rosa, NM 88435</td>
<td>472-3459</td>
</tr>
<tr>
<td>Harding</td>
<td>3112 Hot Springs Blvd.</td>
<td>Las Vegas, NM 87701</td>
<td>425-6741</td>
</tr>
<tr>
<td>Hidalgo</td>
<td>109 Poplar St.</td>
<td>Lordsburg, NM 88045</td>
<td>542-3562</td>
</tr>
<tr>
<td>Lea</td>
<td>2120 N. Alto, Suite D</td>
<td>Hobbs, NM 88240</td>
<td>397-3400</td>
</tr>
<tr>
<td>Lincoln</td>
<td>26387 Hwy 70</td>
<td>Ruidoso, NM 88346</td>
<td>378-1762</td>
</tr>
<tr>
<td>Luna</td>
<td>910 E. Pear</td>
<td>Deming, NM 88031</td>
<td>546-0467</td>
</tr>
<tr>
<td>McKinley</td>
<td>2907 E. Aztec Avenue</td>
<td>Gallup, NM 87301</td>
<td>863-9545</td>
</tr>
<tr>
<td>Mora</td>
<td>3113 Hot Springs Blvd.</td>
<td>Las Vegas, NM 897701</td>
<td>425-6741</td>
</tr>
<tr>
<td>Otero</td>
<td>2000 Juniper</td>
<td>Alamogordo, NM 88310</td>
<td>437-9260</td>
</tr>
<tr>
<td>Quay</td>
<td>421 W. Tucumcari Blvd.</td>
<td>Tucumcari, NM 88401</td>
<td>461-4627</td>
</tr>
<tr>
<td>Rio Arriba</td>
<td>228 Onate Street</td>
<td>Española, NM 87532</td>
<td>753-2271</td>
</tr>
<tr>
<td>Rio Arriba</td>
<td>17345 Chama Highway</td>
<td>Tierra Amarilla, NM 87575</td>
<td>588-7103</td>
</tr>
<tr>
<td>Roosevelt</td>
<td>1028 Community Way</td>
<td>Portales, NM 88130</td>
<td>356-4473</td>
</tr>
<tr>
<td>Sandoval</td>
<td>830 Camino Del Pueblo</td>
<td>Bernalillo, NM 87004</td>
<td>867-3357</td>
</tr>
<tr>
<td>San Juan</td>
<td>101 W. Animas</td>
<td>Farmington, NM 87499</td>
<td>566-9600</td>
</tr>
<tr>
<td>San Miguel</td>
<td>3112 Hot Springs Blvd.</td>
<td>Las Vegas, NM 87701</td>
<td>425-6741</td>
</tr>
<tr>
<td>Santa Fe</td>
<td>2542 Cerrillos Road</td>
<td>Santa Fe, NM 87502</td>
<td>827-1932</td>
</tr>
<tr>
<td>Sierra</td>
<td>102 Barton Street</td>
<td>T or C, NM 87901</td>
<td>894-3011</td>
</tr>
<tr>
<td>Socorro</td>
<td>1014 N. California St.</td>
<td>Socorro, NM 87801</td>
<td>835-0342</td>
</tr>
<tr>
<td>Taos</td>
<td>145 Roy Rd.</td>
<td>Taos, NM 87571</td>
<td>758-8804</td>
</tr>
<tr>
<td>Torrance</td>
<td>109 Tulane Ave.</td>
<td>Moriarty, NM 87035</td>
<td>832-5026</td>
</tr>
<tr>
<td>Union</td>
<td>834 Main Street</td>
<td>Clayton, NM 88415</td>
<td>374-9401</td>
</tr>
<tr>
<td>Valencia</td>
<td>100 N. 5th Street</td>
<td>Belen, NM 87002</td>
<td>864-5200</td>
</tr>
<tr>
<td>Valencia</td>
<td>445 Camino Del Ray, Suite B</td>
<td>Los Lunas, NM 87031</td>
<td>222-0800</td>
</tr>
</tbody>
</table>

Section I – Family Handbook I-45
Section II

Care Notebook
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:

<table>
<thead>
<tr>
<th>Name/Relationship</th>
<th>Home #</th>
<th>Work #</th>
<th>Cell #</th>
<th>Pager #</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Child’s Name: ________________________________

Primary and Secondary Diagnosis:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**

<table>
<thead>
<tr>
<th>Type of Surgery / Procedure</th>
<th>Surgeon / Physician / Hospital</th>
<th>Date(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**HOSPITAL ADMISSIONS (for reasons other than surgery)**

<table>
<thead>
<tr>
<th>Reason for Admission</th>
<th>Hospital</th>
<th>Date(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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

☐ Computer ☐ Lip-Reads
☐ Communication Board ☐ Interpreter Services
☐ Sign Language (ASL) ☐ Communication Book
☐ Sign Language (English) ☐ Other

DEVELOPMENTAL SCREENING

At what age level is your child functioning: cognitively ________ motor skills ______
Last Date Tested: __________ By Whom: _______________ Where: ________________

Ambulation: ☐ Walks Independently ☐ Walks With Assistance
☐ Walks With Walker/Brace, Etc. ☐ Non-Ambulatory
☐ Uses Wheelchair With Assist. ☐ Motorized
☐ Uses Wheelchair w/o Assist. ☐ Motorized

Transfer Directions:

☐ Independent ☐ With Assist ☐ Equipment Type
☐ Pivot Transfer ☐ 1 or 2 Person Lift ☐ Other

Feeding:

☐ Regular Diet ☐ No Assist
☐ Soft Diet ☐ Partial Assist ☐ Special Dishes or
☐ Pureed ☐ Total Assist ☐ Pureed Finger Foods
☐ Utensils ☐ Feeding Pump
Child’s Name: __________________________________

<table>
<thead>
<tr>
<th>Hygiene:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Box No Assistance</td>
<td></td>
</tr>
<tr>
<td>Box Partial Assistance</td>
<td></td>
</tr>
<tr>
<td>Box Totally Assisted</td>
<td></td>
</tr>
<tr>
<td>Box Bath Chair or Shower Equipment</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Toileting:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Box Fully Toilet Trained</td>
<td></td>
</tr>
<tr>
<td>Box No Assistance</td>
<td></td>
</tr>
<tr>
<td>Box Diapers at Night</td>
<td></td>
</tr>
<tr>
<td>Box Partial Assistance</td>
<td></td>
</tr>
<tr>
<td>Box Diaper Dependent</td>
<td></td>
</tr>
<tr>
<td>Box Full Assistance</td>
<td></td>
</tr>
<tr>
<td>Box Intermittent Catheterization Program</td>
<td></td>
</tr>
<tr>
<td>Frequency _____________</td>
<td></td>
</tr>
<tr>
<td>Technique _______________</td>
<td></td>
</tr>
<tr>
<td>Box Independent</td>
<td></td>
</tr>
<tr>
<td>Box Needs Assistance</td>
<td></td>
</tr>
<tr>
<td>Box Bowel Management Program</td>
<td></td>
</tr>
</tbody>
</table>
Child’s Name: ____________________________________________

**Monthly Weight Chart**

<table>
<thead>
<tr>
<th>Date / Year</th>
<th>Weight in lbs.</th>
<th>Change +/-</th>
<th>Date / Year</th>
<th>Weight in lbs.</th>
<th>Change +/-</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td></td>
<td></td>
<td>July</td>
<td></td>
<td></td>
</tr>
<tr>
<td>February</td>
<td></td>
<td></td>
<td>August</td>
<td></td>
<td></td>
</tr>
<tr>
<td>March</td>
<td></td>
<td></td>
<td>September</td>
<td></td>
<td></td>
</tr>
<tr>
<td>April</td>
<td></td>
<td></td>
<td>October</td>
<td></td>
<td></td>
</tr>
<tr>
<td>May</td>
<td></td>
<td></td>
<td>November</td>
<td></td>
<td></td>
</tr>
<tr>
<td>June</td>
<td></td>
<td></td>
<td>December</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date / Year</th>
<th>Weight in lbs.</th>
<th>Change +/-</th>
<th>Date / Year</th>
<th>Weight in lbs.</th>
<th>Change +/-</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td></td>
<td></td>
<td>July</td>
<td></td>
<td></td>
</tr>
<tr>
<td>February</td>
<td></td>
<td></td>
<td>August</td>
<td></td>
<td></td>
</tr>
<tr>
<td>March</td>
<td></td>
<td></td>
<td>September</td>
<td></td>
<td></td>
</tr>
<tr>
<td>April</td>
<td></td>
<td></td>
<td>October</td>
<td></td>
<td></td>
</tr>
<tr>
<td>May</td>
<td></td>
<td></td>
<td>November</td>
<td></td>
<td></td>
</tr>
<tr>
<td>June</td>
<td></td>
<td></td>
<td>December</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date / Year</th>
<th>Weight in lbs.</th>
<th>Change +/-</th>
<th>Date / Year</th>
<th>Weight in lbs.</th>
<th>Change +/-</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td></td>
<td></td>
<td>July</td>
<td></td>
<td></td>
</tr>
<tr>
<td>February</td>
<td></td>
<td></td>
<td>August</td>
<td></td>
<td></td>
</tr>
<tr>
<td>March</td>
<td></td>
<td></td>
<td>September</td>
<td></td>
<td></td>
</tr>
<tr>
<td>April</td>
<td></td>
<td></td>
<td>October</td>
<td></td>
<td></td>
</tr>
<tr>
<td>May</td>
<td></td>
<td></td>
<td>November</td>
<td></td>
<td></td>
</tr>
<tr>
<td>June</td>
<td></td>
<td></td>
<td>December</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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: _________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________
<table>
<thead>
<tr>
<th>Date</th>
<th>Providers</th>
<th>Questions / Concerns to be Discussed</th>
<th>Reason Seen / Care Provided</th>
<th>Next Appointment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Steps to a Satisfactory Medical Appointment:**
1. Write down your problems/questions before you go.
2. Number the problems in questions. Make the **Number One** the most important.
3. Show the provider your list. Write down any answers to your questions.
4. Talk to the provider about options for handling your problems/questions.
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.

1. Describe your child’s favorite things to do.

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

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

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
3. Describe how your child shows affection, shares feelings, or plays with other children.

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

4. Describe how your child communicates and understands others. (Include special words your family and child uses to describe things.)

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

5. Describe your child’s way of asking for help.

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

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.
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________
<table>
<thead>
<tr>
<th>TIME</th>
<th>Care Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Afternoon</td>
<td></td>
</tr>
<tr>
<td>*Evening</td>
<td></td>
</tr>
</tbody>
</table>
Section II – Care Notebook

<table>
<thead>
<tr>
<th>*Bedtime</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
Only use this log if it applies to your child.

<table>
<thead>
<tr>
<th>Date / Time</th>
<th>Duration of Seizure / Behavior</th>
<th>Description of Seizure (extremities involved, intensity) / or Behavior Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Medication Log

<table>
<thead>
<tr>
<th>DATE STARTED</th>
<th>DATE STOPPED</th>
<th>MEDICATION</th>
<th>WHAT IT IS FOR</th>
<th>DOSE / ROUTE</th>
<th>TIME GIVEN</th>
<th>PRESCRIBED BY</th>
<th>SIDE EFFECTS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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: ___________________________
These are disposable supplies you need to re-order monthly. For example: catheters, feeding bags, formula, saline, gauze, syringes, etc. Use a separate sheet for each supplier.

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
<th>Manufacturer</th>
<th>Order Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Description</td>
<td>Amount</td>
<td>Manufacturer</td>
<td>Order Number</td>
</tr>
<tr>
<td>-------------</td>
<td>--------</td>
<td>--------------</td>
<td>--------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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:  

______________________________________________________________________  

______________________________________________________________________  

______________________________________________________________________  

______________________________________________________________________
Your child and family will experience many transitions, small and large, over time. Three predictable transitions will occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Many children do not experience these transitions in the way most children experience them. Other transitions may involve moving into new programs, with new agencies and care providers, or making new friends. Transitions involve changes; adding new expectations, responsibilities or resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to be done today. You may find it helpful to jot down a few ideas about your child and family’s future. You might start by thinking about your child and family’s strengths. How can these strengths help plan for “what’s next” and for reaching long-term goals? What are your dreams and your fears about your child and family’s future?

Notes:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
Additional Notes
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.
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.)_____
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

<table>
<thead>
<tr>
<th>Agency Name</th>
<th>Contact Person</th>
<th>Phone Number</th>
<th>Reason Used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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 ________________________________________________________________
Letters of Guardianship have been approved by:

Judge ___________________________ Date ___________________________

<table>
<thead>
<tr>
<th>Approved Guardian’s Name</th>
<th>Address</th>
<th>Phone Number</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>________________________</td>
<td>_______</td>
<td>____________</td>
<td>____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approved Successor Guardians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
</tr>
<tr>
<td>--------------------------</td>
</tr>
<tr>
<td>________________________</td>
</tr>
<tr>
<td>________________________</td>
</tr>
</tbody>
</table>

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.
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.”


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.”


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
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

Protection and Advocacy System
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.

♦ **Protection and Advocacy System (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
1. Celebrate my child

What this means to my family
♦ 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.

Celebrar a mi hijo/a

Qué significa esto para mi familia
♦ Celebra a mi hijo/a

Ideas we came up with today:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

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.

2. Choose to focus on what’s going right

What this means to my family
♦ 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.

Concentrarme en lo que va bien

Qué significa esto para mi familia
♦ Concentrarme en lo que va bien
Ideas we came up with today:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

3. **Get beyond the “why?” to the “how?”**

*What this means to my family*

♦ 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*

♦ 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.

*What this means to my family*

♦ 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**

*What this means to my family*

♦ A 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*

♦ 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.
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 we came up with today:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

5. Trust my instincts

What this means to my family

♦ 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 we came up with today:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

6. Don’t go it alone: ask for help

What this means to my family

♦ 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:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
♦ 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 we came up with today:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

7. **Reassess success**

*What this means to my family*  
♦ 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.

*Evaluar los éxitos*  
♦ 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

What this means to my family
♦ 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.

What this means to my family
♦ 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

What this means to my family
♦ 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.

<table>
<thead>
<tr>
<th>Ideas I can try // Ideas que puedo usar</th>
</tr>
</thead>
</table>

♦ 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

What this means to my family

♦ 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!”

<table>
<thead>
<tr>
<th>Ideas I can try // Ideas que puedo usar</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th>Ideas I can try //</th>
<th>Ideas que puedo usar</th>
</tr>
</thead>
</table>

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

Idea we came up with today:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

12. Give myself a “time out”

<table>
<thead>
<tr>
<th>Ideas I can try //</th>
<th>Ideas que puedo usar</th>
</tr>
</thead>
</table>

◆ 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.

Idea 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.

<table>
<thead>
<tr>
<th>Ideas I can try</th>
<th>Ideas que puedo usar</th>
</tr>
</thead>
<tbody>
<tr>
<td>♦ Talk with someone you’re close with to play this role for and with you.</td>
<td></td>
</tr>
<tr>
<td>♦ 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.”</td>
<td></td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Ideas I can try</th>
<th>Ideas que puedo usar</th>
</tr>
</thead>
<tbody>
<tr>
<td>♦ Set up a regular date.</td>
<td></td>
</tr>
<tr>
<td>♦ Take time to talk about something other than the kids, bills, school, and work/life stresses.</td>
<td></td>
</tr>
<tr>
<td>♦ Remember to be affectionate with each other – touch is powerful and we all need it.</td>
<td></td>
</tr>
</tbody>
</table>
Ideas we came up with today:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

15. Be a family

*What this means to my family*

- 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.

<table>
<thead>
<tr>
<th>Ideas I can try // Ideas que puedo usar</th>
</tr>
</thead>
<tbody>
<tr>
<td>♦ 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.</td>
</tr>
</tbody>
</table>

Ideas we came up with today:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

16. Balance time together with each of my children

*What this means to my family*

- 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.

Ideas we came up with today:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

17. Know what I want and go for it

Sabir lo que quiero y conseguirlo

What this means to my family

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

**What this means to my family**

♦ 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**

♦ 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.

19. Connect with other parents

**What this means to my family**

♦ 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**


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  

What this means to my family  

- 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

- Spend some time reflecting on what has been valuable (rewarding) in having a child like yours, and then share your journey with others.

Ideas we came up with today:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
<table>
<thead>
<tr>
<th>Other Strategies</th>
<th>Otras Estrategias</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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.

**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 to remove some of the barriers to good communication.

**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.

---

**Communication - Messages We Give and Get**

**Skills that Enhance Communication**
- Concentration
- Interest
- Reporting
- Understanding
- Retaining of Information
- Explaining
- Interpreting

**What Can Block Communication?**
- Emotions, Feelings
- Attitudes
- Body Language
- Inequality
- Lack of Respect
- Withholding Information
- Jargon (Medical, Technical)
- Lack of Knowledge
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.

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.

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 Leaning 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)

<table>
<thead>
<tr>
<th>Date / Time</th>
<th>Message / Concern / Reason for the Discussion</th>
<th>Time of Call Back / Who &amp; What Said</th>
<th>Outcome / Results / Follow-up if Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Communication Log

<table>
<thead>
<tr>
<th>Date / Time</th>
<th>Message / Concern / Reason for the Discussion</th>
<th>Time of Call Back / Who &amp; What Said</th>
<th>Outcome / Results / Follow-up if Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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

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

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.
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 you 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 impacts 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 growth-ful 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.

**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.

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.

**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.
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).

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: ______________________________________