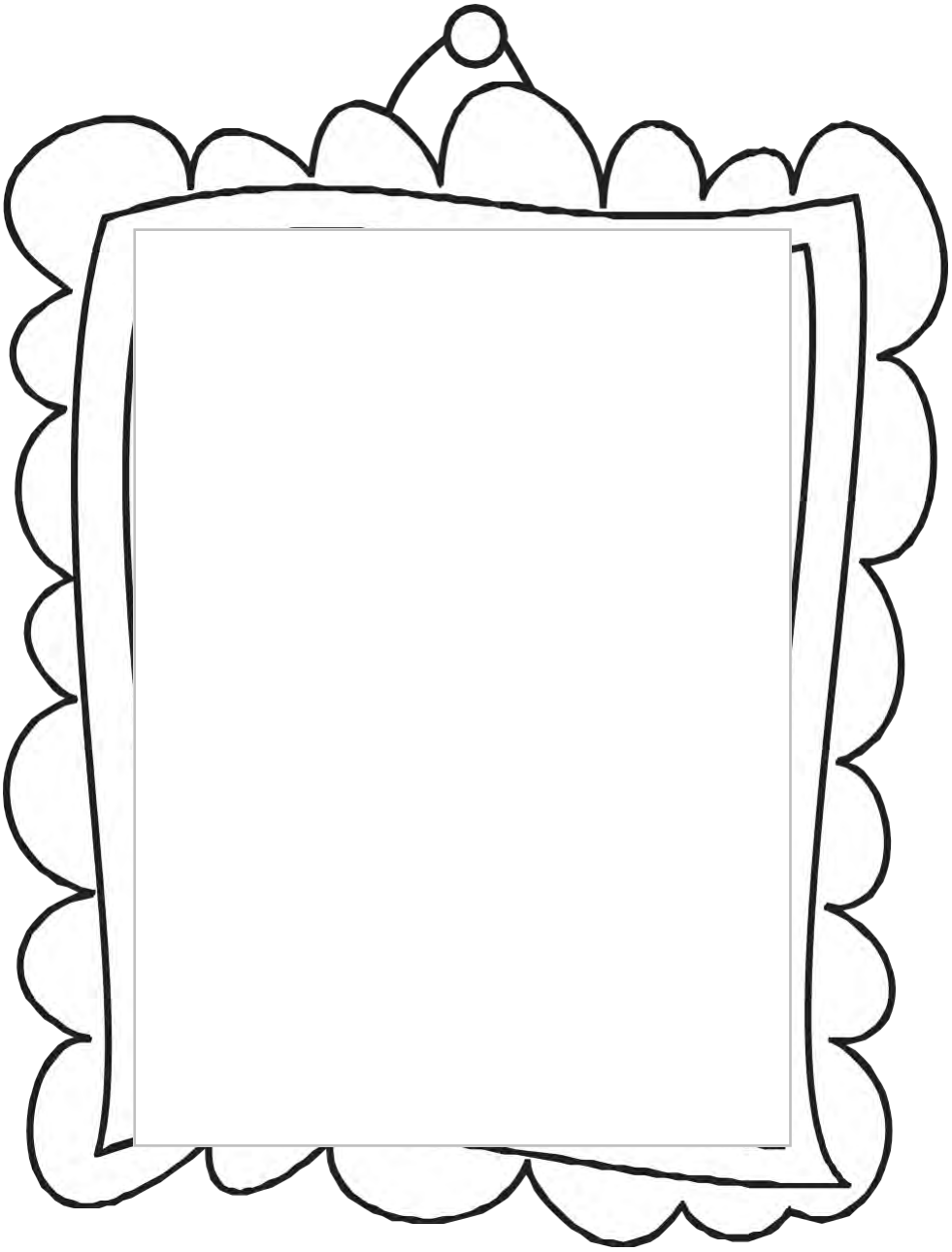
AMCSI
Arthrogryposis Multiplex Congenita Support, Inc.

My Book of Knowledge



This book is all about _____

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ABOUT YOUR CARE NOTEBOOK

What is a Care Notebook?

A Care Notebook is a great tool for families who have children with special health care needs. Using this Care Notebook will help keep track of any important information involved in your child's health care journey.

How can a Care Notebook help me?

Your child may have many different sources providing information and paperwork, this Notebook will help keep everything organized. Having one central place for this information will make it easier for you to find and share with others who are a part of your child's care team.

Why build my own Care Notebook?

Building this Care Notebook becomes very personal to your child and ideally should be customized to reflect your child's medical history and current information.

Fill and update your Care Notebook:

- Track changes in your child's medicines or treatments
- Add new information to the Care Notebook
- List telephone numbers for providers and contacts
- Prepare for appointments
- File information about your child's health history

Use your Care Notebook

- Keep your Care Notebook where it is easy to find. This helps you and anyone who needs information when you are not there.
- Share new information with your child's primary care physician, school nurse, daycare staff, and others caring for your child.
- Take the Care Notebook with you to appointments and hospital visits so that the information you may need is easily accessible.
- Include your child when working on the Care Notebook. Let them know that the Care Notebook contains information about them and their care.

SETTING UP YOUR CARE NOTEBOOK

Follow these steps to get started using your Care Notebook:

Step 1: Gather the information you already have.

- Gather up any health information about your child you already have. This may include reports from recent doctor's visits, recent summary of hospital stays, this year's school plan, or test results.

Step 2: Check out the pages of the Care Notebook

- Which of these pages could help you keep track of information about your child's health or care?

Step 3: Decide which information is most important to keep in your child's Care Notebook

- Which information do you look up often?
- What information do caregivers for your child need?
- Consider storing other information in a space that is easily accessible in case it is needed in the future.

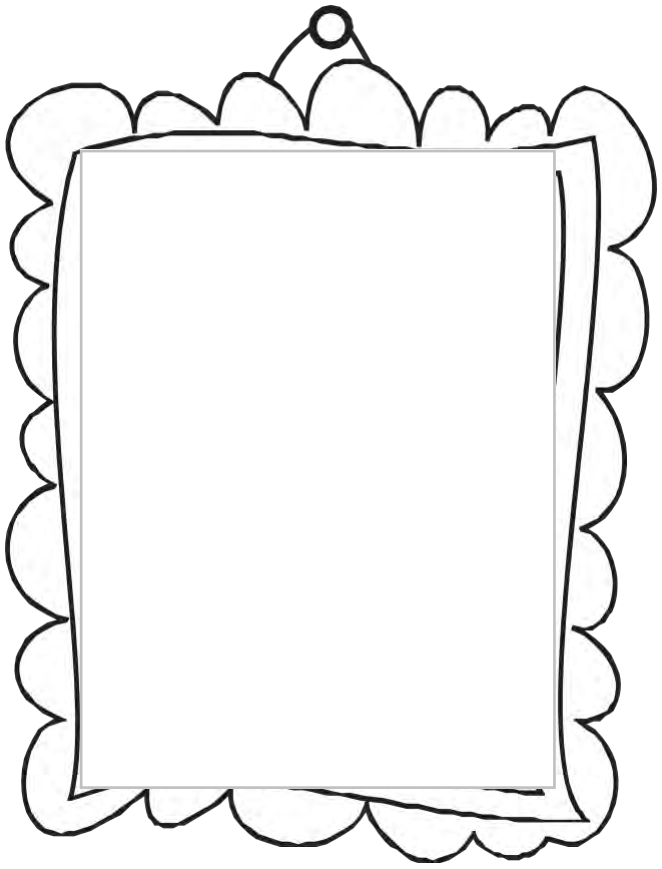
Step 4: Assemble your Care Notebook

- Everyone has a different way of organizing information. The KEY is to make it easy for you.

Use this “Myself” section of your Care Notebook to create an identity profile for your child. This section includes a personal profile, family, friends and a calendar to schedule your child’s appointments & activities.

MYSELF

BIOGRAPHY PAGE



My name is:

_____

My nickname is:

_____

My birthday is:

_____

My favorite thing to do is:

_____

My least favorite thing to do is:

_____

My friends are _____

My caregivers are _____

When I am happy I _____

When I am sad I _____

When I feel pain I _____

I need help with _____

I can do these things for myself _____

My Favorite Things:

Toys _____
TV Shows _____
Games _____
Hobbies _____
Songs _____
Favorite foods _____
Least Favorite foods _____

FAMILY INFORMATION

Child's Name: _____
Nickname: _____
Date of Birth: _____
Social Security Number: _____
Diagnosis: _____
Blood Type: _____

Legal Guardian: _____
Address: _____
Phone: _____
Alt Phone: _____

Mother's Name: _____
Address: _____
Daytime Phone: _____
Evening Phone: _____

Father's Name: _____
Address: _____
Daytime Phone: _____
Evening Phone: _____

-Other household members:
Name: _____ Age: _____
Name: _____ Age: _____
Name: _____ Age: _____
Name: _____ Age: _____

Important Family information:
_____
_____
_____
_____

Language(s) spoken at home: _____
Interpreter needed? Yes: ___ No: ____

Emergency Contact
Name: _____
Address: _____
Daytime Phone: _____
Evening Phone: _____

MY HEALTH CARE

The “My Health Care” section of your Care Notebook is to keep all information about your child’s health care and health care needs. This section will be very helpful at appointments with doctors and specialists.

	Doctor's Name	Appointment Date	Appointment Time	Questions to ask at App
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				

	Doctor's Name	Appointment Date	Appointment Time	Questions to ask at App
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				

DIAGNOSES

Child's Name: _____
Date of birth: _____

Diagnosis Given	Provider who gave the diagnosis	Date Noted	Notes

NUTRITION

Describe foods and any nutritional formulas your child takes:	Describe any feeding techniques, precautions or equipment used for feedings:
List any food allergies or restrictions:	Describe any special mealtime routines:

DIET TRACKING FORM

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

GROWTH TRACKING

Date	Height	Weight	Head Circumference	Checked By

IMMUNIZATIONS

	Date	Physician	Date	Physician	Date	Physician	Date	Physician	Date	Physician
Hepatitis B										
Diphtheria-Tetanus										
Diphtheria-Pertussis-Tetanus										
Tetanus										
Polio										
Influenza Type B										
Measles, Mumps & Rubella										
Measles (rubeola)										
Mumps										
Rubella (3 day measles)										
Varicella										
Tuberculin Test										
Lead Screening										
other										

CATHETERIZATION SCHEDULE

Catheterization Information: _____

Month: _____

Date	Time	Amount of Urine Obtained	Additional Comments

Date	Time	Amount of Urine Obtained	Additional Comments

Date	Time	Amount of Urine Obtained	Additional Comments

Date	Time	Amount of Urine Obtained	Additional Comments

NEBULIZER TREATMENTS AND VEST TREATMENTS

Signature: _____ Initials: ____
Signature: _____ Initials: ____
Signature: _____ Initials: ____
Signature: _____ Initials: ____

Date	Time	Neb Given	O2sat pre	O2stat post	Vest Given	O2sat pre	O2 sat post	Comments	Initials

NEBULIZER TREATMENTS AND VEST TREATMENTS

Signature: _____ Initials: ____
Signature: _____ Initials: ____
Signature: _____ Initials: ____
Signature: _____ Initials: ____

Date	Time	Neb Given	O2sat pre	O2stat post	Vest Given	O2sat pre	O2 sat post	Comments	Initials

ALLERGY RECORD

Allergy	Type of Reaction	Date

MEDICATIONS

Name of Medication	Prescription Number	Pharmacy	Strength	Reason of Medication	Dosage/ Frequency	Route (How taken)	State Date	End Date	Reason for ending Medication

Pharmacy:
Address:
Pharmacist:
Phone Number:

RESPIRATORY CARE

Describe the care or treatments you child needs:	Describe any special techniques:
Describe any precautions you use when giving care:	Describe any special routines your child has:

LAB WORK / TEST

Date	Test	Result	Comments

SURGERIES OR PROCEDURES

Type of Surgery/Procedure	Surgeon/Physician/Hospital	Dates

HOSPITAL ADMISSIONS (FOR ANY REASONS OTHER THAN SURGERY)

Reason	Surgeon/Physician/Hospital	Dates

SEIZURE OR BEHAVIOR

☐ Not Applicable to my child

Date	Time	Duration of seizure or behavior	Description of Seizure (extremities involved, intensity, etc) or Behavior you are concerned about

SEIZURE OR BEHAVIOR

☐ Not Applicable to my child

Date	Time	Duration of seizure or behavior	Description of Seizure (extremities involved, intensity, etc) or Behavior you are concerned about

DENTAL RECORD

Dentist's Name: _____
Address: _____
Telephone: _____

All children should have routine dental care. Such care may be even more important when your child has a special care need. He or she may need to be followed by a dentist with special skills. Consults with your family dentist or your child's medical specialist to determine if he or she requires specialized dental services.

Before your child is examined, the dentist should have information regarding your child's medical condition and current care. Any precautions recommended by your child's medical specialist should be discussed with the dentist. It is also essential that you provide the dentist with a list of current medications received by your child.

You may wish to use the space below to keep track of your child's dental appointments.

Date	Time	Appointment Information

EVENT DIARY

Use this sheet to keep track of important events that are related to your child's health. Examples: behaviors, seizures, oxygen requirements, frequency of suctioning, and vomiting.

Date	Activity / Information

MONTHLY MEDICAL SUPPLIES

Vendor Name: _____
Phone: _____
Fax: _____

Product Description	Product Code	Quantity	Received	Back Order	Comments

NOTES

MY CONTACTS

Use the “My Contacts” section for your Care Notebook for the people who provide services and give care to your child.

HEALTHCARE PROVIDERS

Primary Medical Provider: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Preferred Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Specialty Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Specialist Name: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Specialist Name: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Specialist Name: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Specialist Name: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Specialist Name: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Dentist Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Orthodontist Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Public Health Nurse: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Nutritionist: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Health Family Contact: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Health Family Contact: _____
Clinic/Hospital: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Home Health Agency: _____
Start Date: _____ End Date: _____
Contact Person: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Home Health Agency: _____
Start Date: _____ End Date: _____
Contact Person: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Home Health Agency: _____
Start Date: _____ End Date: _____
Contact Person: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Pharmacy: _____
Contact Person: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Pharmacy: _____
Contact Person: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Occupational Therapist (OT): _____
Start Date: _____ End Date: _____
Agency: _____
Address: _____
_____ City: _____ State: _____
Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Physical Therapist (PT): _____
Start Date: _____ End Date: _____
Agency: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Speech – Language Pathologist: _____
Start Date: _____ End Date: _____
Agency: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Other Therapist: _____
Start Date: _____ End Date: _____
Agency: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

FAMILY SUPPORT RESOURCES

Parent-to-parent: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Parent Group: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Religious Organization: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Service Organization: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Counseling Services: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

Other: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

School/Preschool: _____
Principal: _____ School Contact: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (___) _____
Email: _____

School Nurse: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Teacher: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Special Education Teacher: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Other: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Transportation Agency: _____
Contact Person: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____

Transportation Agency: _____
Contact Person: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____

Respite Care Provider: _____
Start Date: _____ End Date: _____
Agency: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

Respite Care Provider: _____
Start Date: _____ End Date: _____
Agency: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (____) _____ Fax: (____) _____
Email: _____

SCHOOL CONTACTS

School District: _____
Address: _____
Phone: (___)_____ Fax: (___)_____

Special Education Coordinator: _____
Address: _____
Phone: (___)_____ Fax: (___)_____

504 Accommodation Plan Coordinator: _____
Address: _____
Phone: (___)_____ Fax: (___)_____

District Nurse assigned to your child's school: _____
Address: _____
Phone: (___)_____ Fax: (___)_____

School/Preschool: _____
Address: _____
Phone: (___)_____ Fax: (___)_____

Principal/ Administrator: _____
Address: _____
Phone: (___)_____ Fax: (___)_____
Classroom

Teacher:_____
Address: _____
Phone: (___)_____ Fax: (___)_____
Resource

Teacher:_____
Address: _____
Phone: (___)_____ Fax: (___)_____

Aide/Assistant/Intervener: _____
Address: _____
Phone: (___)_____ Fax: (___)_____

Special Education Director/
Teacher(s):_____
Address: _____
Phone: (___)_____ Fax: (___)_____

EMERGENCY CONTACTS

Name:_____
Relationship: _____
Address: _____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____
City: _____ State: _____ Zip: _____ Phone: _____

PERSONAL CONTACTS

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

Name:_____
Relationship: _____
Address: _____Email:_____
City: _____ State: _____ Zip: _____ Phone: _____

MY PLAN

The “My Plan” section of your Care Notebook is where you can lay out what is happening in your child’s life and what you would like to see happen in the future. This includes daily care, mealtime routines, therapies, recreation, and more.

CARE SCHEDULE

Time	Care
Morning	
Afternoon	

CARE SCHEDULE

Time	Care
Evening	
Night	

MEALTIME ROUTINE

Usual eating times: _____
Usual length of time to eat: _____

Food Allergies:	Foods to Avoid:
Favorite Foods:	Food Dislikes:

Feeding equipment / utensils used / positioning:

_____
_____
_____

Feeding tips:

_____
_____
_____
_____
_____

THERAPY

Type: ☐ Physical ☐ Occupational ☐ Speech ☐

Month/year: _____

			WEEKLY: A=achieved - C=continue				
#	Goals	Comments	1	2	3	4	5

COMMUNICATION

Special Words	Meaning of the word

DAILY LIVING ACTIVITIES

Describe your child's abilities to feed him or herself, bathe, get dressed, use the bathroom, brush teeth, comb hair, etc. What can your child do by his or herself and is any help involved like equipment? Describe any special routines your child has for bath time, getting dressed, etc.

MOBILITY

Describe how your child gets around:	What can your child do by him or herself:
Describe any help or equipment your child uses to get around:	Describe any activity limits and any special routines your child must transfer, pressure releases, positioning, etc.:

COMMUNICATION

Describe how your child communicates to others. Does he or she use gestures, sign language words, equipment? What are some special words your family or child use to describe things?

COPING / STRESS TOLERANCE

Describe how your child copes with stress. Is it stressful when your child meets new people or situations, hospital stays, procedures or having blood drawn? What upsets your child, and what does he or she do when he or she has “had enough” moment? What is their way of asking for help, things to do, or say to comfort your child?

COPING / STRESS TOLERANCE

Jot down some ideas about your child’s and family’s strengths. How can these strengths help plan for the “what’s next”? What are some ideas on how to reach the long-term goals? What are your dreams and fears about your child’s or family's future?

SOCIAL EXPERIENCES

What activities are meaningful for your son or daughter? Make a list of places and situations that your child is uncomfortable with or dislikes. What leisure activities does your child enjoy?

Favorite TV shows/movie:

Hobbies/Activities in the home:

Leisure Activities/Clubs outside the home:

Name of Club: _____
Contact person: _____
Phone number: _(___)_____ How often: _____

Name of Club: _____
Contact person: _____
Phone number: _(___)_____ How often: _____

Special Interests: (Example: loves Hershey Bears games in person but not on TV)

Favorite Vacations/Travels:

SOCIAL / PLAY

Describe how your child shows affection, shares feelings, or plays with other children:	Describe what works best to help your child get along or cooperate with others:
Describe your child's favorite things to do:	Include any special family activities or customs that are important:

REST / SLEEP

Describe your child's ability to get to sleep:	Describe your child's bedtime routines:
Any security or comfort objects used:	Additional notes:

MY COVERAGE

The “My coverage” section is where you can record all information on Health Care Coverage

INSURANCE

Insurance Name: _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____

Phone: _(___)_____ Fax: _(___)_____

Medicaid (HMO Name is applicable– this is the company name that appears above your child's name and ID number on the Medicaid identification card): _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____

Phone: _(___)_____ Fax: _(___)_____

Insurance Name: _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____

Phone: _(___)_____ Fax: _(___)_____

Supplemental Security Income (SSI):: _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____

Phone: _(___)_____ Fax: _(___)_____

Other: _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____

Phone: _(___)_____ Fax: _(___)_____

MEDICAL TRAVEL EXPENSE

Date	Travel From	Travel To	Miles	Reason for Travel	Amount of Total Spending

OUT OF POCKET EXPENSE LOG

Date	Item Description/#	Cost

TRANSPORTATION / TRAVEL

PARENT CAREGIVER

BATHROOM / SHOWER

SCHOOL / AIDES / PARAPROFESSIONAL