



STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

201 W. Preston Street • Baltimore, Maryland 21201

Martin O'Malley, Governor – Anthony G. Brown, Lt. Governor – Joshua M. Sharfstein, M.D., Secretary

Dear Family,

This care notebook has been designed for you, the parents and caregivers of a child with special health care needs. You play a central role in your child's care and doctors and nurses rely on you to give them information about your child's progress or your concerns. It is helpful to have all the information you need in one place and organized so that you can find it easily. This notebook is a start, but you can certainly "customize" it any way you would like (see Creating Your Care Notebook on the following page).

The Office for Genetics and People with Special Health Care Needs (OGPSHCN) is also a resource for information you may need about services for your child. Please feel free to contact us at the numbers below, especially our Children's Resource Line:

<b>Birth Defects Reporting &amp; Information System</b>	410-767-6625	
<b>Children's Health Resource Line</b>	410-767-5585	<b>or</b> 1-800-638-8864
<b>Children's Medical Services</b>	410-767-5164	
<b>Infant Hearing Services</b>	410-767-6432	<b>or</b> 1-800-633-1316
<b>Sickle Cell Disease Services</b>	410-767-6737	
<b>Specialty Care Services</b>	410-767-5592	
<b>Transition Services</b>	410-767-6659	

Our resource map on the web at <http://specialneeds.dhmh.maryland.gov/> to provide a list of resources by type and location across Maryland. Congratulations on the new addition to your family and we hope you find these resources helpful.

Sincerely,

Donna X. Harris  
Director  
Office for Genetics and People with Special Health Care Needs

Toll Free 1-877-4MD-DHMH – TTY/Maryland Relay Service 1-800-735-2258

Web Site: [www.dhmh.state.md.us](http://www.dhmh.state.md.us)

# Creating Your Care Notebook

## Follow These Steps to Create Your Child's Care Notebook:



### Step 1: Gather existing information

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

### Step 2: Review the Care Notebook

- ◇ Which of these pages could help you keep track of information about your child's health or care?
- ◇ Choose the pages you like. Print copies of any that you think you will use. You can get additional Care Notebook pages at [http://fha.maryland.gov/genetics/care\\_notebook.cfm](http://fha.maryland.gov/genetics/care_notebook.cfm)
- ◇ Here are some websites that have resources for customizing your care notebook:

[http://www.medicalhomeinfo.org/for\\_families/care\\_notebook/care\\_notebook.aspx](http://www.medicalhomeinfo.org/for_families/care_notebook/care_notebook.aspx)

[http://www.delawarefamilytofamily.org/care\\_notebook.htm](http://www.delawarefamilytofamily.org/care_notebook.htm)

<http://cshcn.org/planning-record-keeping/care-notebook>

### Step 3: Decide what to keep in the Care Notebook

- ◇ What information do you look up most often?
- ◇ What information do people caring for your child need?
- ◇ Consider storing other information in a file drawer or box where you can find it if needed.

### Step 4: Put the Care Notebook together

- ◇ Each of us has our own way of organizing information. The key is to make it easy for you to find again.
- ◇ Some suggestions for supplies used to create a Care Notebook:  
**3-ring notebook** or large accordion envelope will hold papers securely.  
**Tabbed dividers** to create your own sections.  
**Pocket dividers** to store reports.  
**Plastic pages** to store business cards and photographs.

## **Working with Your Health Insurer: 10 Tips for Families with Children & Youth with Special Health Care Needs**

- 1) Read the materials you receive from your health plan or employer. These may include your service benefit plan, a directory of network providers and other supplementary information. Many private health insurers send periodic newsletters and health promotion materials. These may help you better understand your health benefits and maximize the services your family is entitled to receive.
- 2) Know your health plan's mission, vision and/or core values statements. These statements generally include phrases about providing members with affordable, accessible care, forming working partnerships, and ensuring a member's peace of mind. These statements can work to your advantage when you are advocating for a service and/or having problems getting a service covered. Frame your argument using the words your insurer has provided.
- 3) If your child has special health needs and requires more services than most children require, ask your insurer for a case manager or care coordinator. This is a free service and can provide a single "go to" person who can help you understand your benefits and make the referral or pre-approval process easier and faster.
- 4) Review every EOBs (Explanation of Benefits) you receive from your health insurer. Check for accuracy, the amounts paid and any co-payments you must pay. This is a good way to avoid billing inaccuracies. It is also a good way to make sure you are not paying for services your child did not receive or for services that your policy should cover.
- 5) When speaking with insurance customer service personnel or case managers, be polite. It is easier to build partnerships and get help when you're cooperative and pleasant; no one wants to help someone who is rude or disrespectful. Even if the person is not able to help you, offer your thanks.
- 6) Work your way up the ladder: If the customer service person or your case manager can't help you, ask to speak to the person who can, such as a supervisor or head of the department.
- 7) Keep a written record of calls and copies of all letters to your health insurer. Write down the names and numbers of the people you speak with and a short summary of your discussion. If you have a problem getting a service covered, it is more effective to say, "I spoke with Ms. Smith on February 1, 2011, and she approved ...." Rather than saying, "The last time I called I spoke with someone, she told me....."
- 8) Insurance companies look at the bottom line: what is this going to cost? Frame your requests in those terms, and in terms of "Medical Necessity." Your health plan will have a definition for "Medical Necessity" in the service benefit plan. For example, tell your insurer, "If you pay for speech and language therapy now, 52 visits a year will cost you \$XXX. If you don't provide this service, augmentative communication/assistive technology will cost you \$XXX in five years when this therapy is no longer an option for my child. RESOURCE: Read example letters of medical necessity at <http://www.medicalhomeportal.org/issue/writing-letters-of-medical-necessity>.
- 9) When you have exhausted the chain of command within your insurance company, you may be able to get help from the Maryland Insurance Administration (MIA). An ombudsman helps families understand their insurance benefits and work through external grievances. They provide assistance if your health plan is based in Maryland, fully insured, and your claim has been denied as "not medically necessary." To learn more about the Maryland Insurance Administration, call 1-800-492-6116 or visit <http://www.mdinsurance.state.md.us/sa/jsp/Mia.jsp>
- 10) For additional help and more information contact:  
The Office of Genetics and Children with Special HealthCare Needs  
Parent Resource Coordinator  
1-800-638-8864  
<http://fha.maryland.gov/genetics/>

This article was adapted from the Massachusetts Family-to-Family Health Information Center @ the Federation for Children with Special Needs.

**MEDICAL SUMMARY FORM**

**Name:** \_\_\_\_\_

**Birth Date:** \_\_\_\_\_

**Medical History/Diagnosis(current):**

**Past Medical History/Diagnosis:**

\* \_\_\_\_\_  
\* \_\_\_\_\_  
\* \_\_\_\_\_  
\* \_\_\_\_\_  
\* \_\_\_\_\_  
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**Medical Professionals:**

**PCP:** \_\_\_\_\_  
**Phone:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_  
**Specialty:** \_\_\_\_\_  
**Phone:** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Birth Date:** \_\_\_\_\_

**\*ALLERGIES\*** \_\_\_\_\_

**Medications:**

<u>Name:</u>	<u>Dose:</u>	<u>Frequency:</u>
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____

**Nutritional Supplements:**

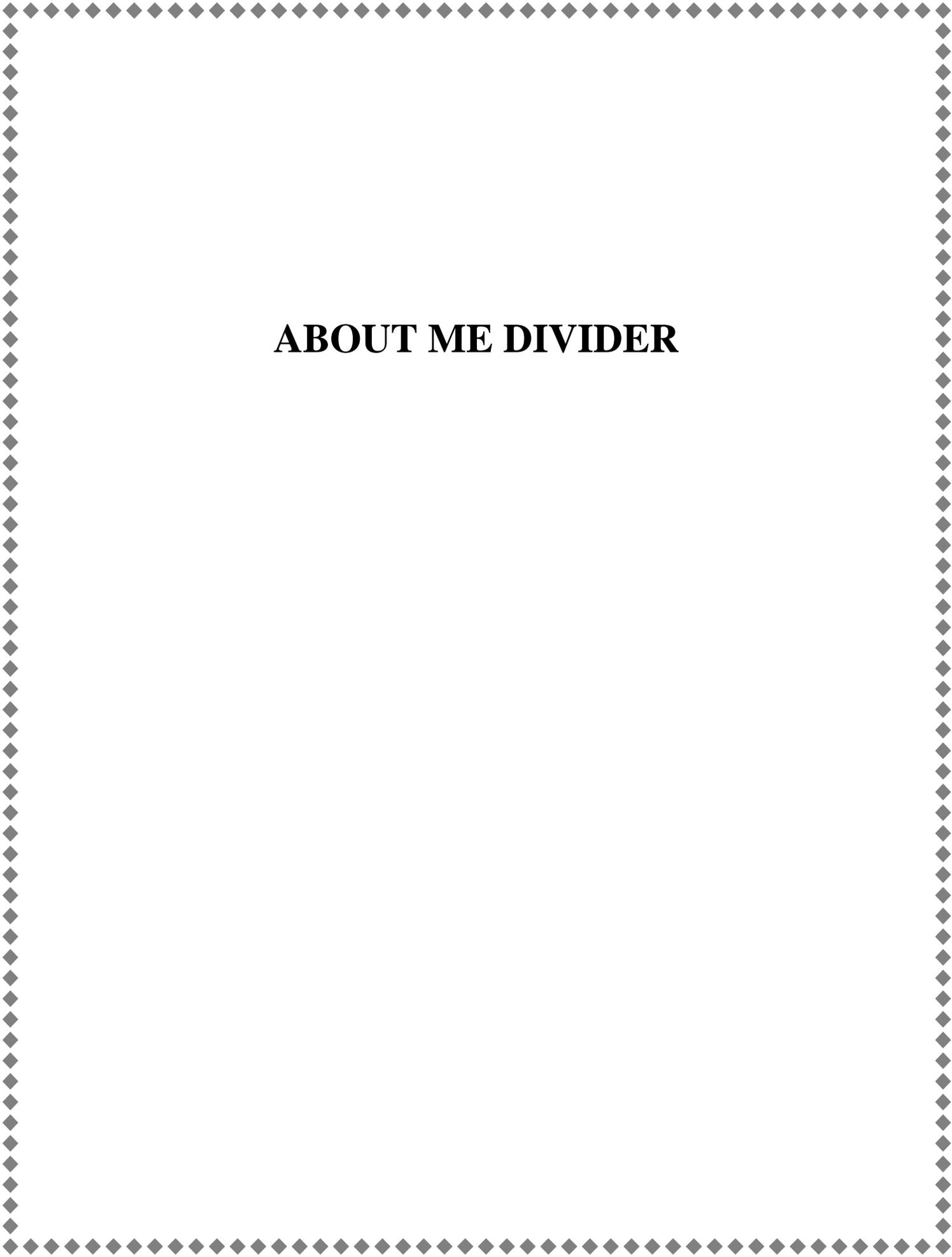
<u>Name:</u>	<u>Dose:</u>	<u>Frequency:</u>
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____

**Daily Procedures:**

* _____
* _____
* _____

**Surgeries/ Hospitalizations(recent):**

<u>Date:</u>	<u>Hospital:</u>	<u>Reason:</u>
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
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* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____



**ABOUT ME DIVIDER**

# All about Me



My name is \_\_\_\_\_  
First Middle Last

My nickname is \_\_\_\_\_

I live at  Home  School  Foster home  
 Hospital  Other \_\_\_\_\_

The names of the people in my family are

First	Last	Relationship to me
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Other people who know me well are (friends, babysitter, neighbors)

First	Last	Relationship to me
_____	_____	_____
_____	_____	_____
_____	_____	_____

## My Pets

My Pet is a \_\_\_\_\_ Name of Pet \_\_\_\_\_

My other pet is a \_\_\_\_\_ Name of Pet \_\_\_\_\_

## Tip:

This form can help providers learn more about your child. It can also teach your child to describe his or her needs, likes, and dislikes. Give your child as much help as he or she needs in filling it out. Update it as your child grows and changes.



# All about Me

Child's Name \_\_\_\_\_

Date of Birth \_\_\_\_\_

## My "Favorites"

Toys \_\_\_\_\_

Games \_\_\_\_\_

Hobbies \_\_\_\_\_

Songs \_\_\_\_\_

TV Shows \_\_\_\_\_

Other \_\_\_\_\_

## Things I like to do during my free time

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Foods I like are

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Foods I don't like are

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I usually go to bed at \_\_\_\_\_ o'clock.

Before bed, I usually \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Things I need help with are (for example: washing up, brushing teeth, dressing, etc.)

\_\_\_\_\_  
\_\_\_\_\_

Things I can do myself are \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

# Family Information

❖ Child's Name: \_\_\_\_\_ Nickname: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Blood type: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Legal Guardian: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Alternate Phone: \_\_\_\_\_

❖ Language Spoken at Home: \_\_\_\_\_

Other language(s): \_\_\_\_\_

Interpreter needed? Yes: \_\_\_\_\_ No: \_\_\_\_\_

Interpreter: \_\_\_\_\_ Phone: \_\_\_\_\_

## Family Members

❖ Mother's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

❖ Father's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

❖ Sibling's Name: \_\_\_\_\_ Age: \_\_\_\_\_

❖ Sibling's Name: \_\_\_\_\_ Age: \_\_\_\_\_

❖ Sibling's Name: \_\_\_\_\_ Age: \_\_\_\_\_

❖ Other household members: \_\_\_\_\_

❖ Important family information: \_\_\_\_\_

## Emergency Contact

❖ Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Alternate Phone: \_\_\_\_\_

## Maryland Care Notebook

(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003.)  
Maryland Department of Health and Mental Hygiene, c. 2007



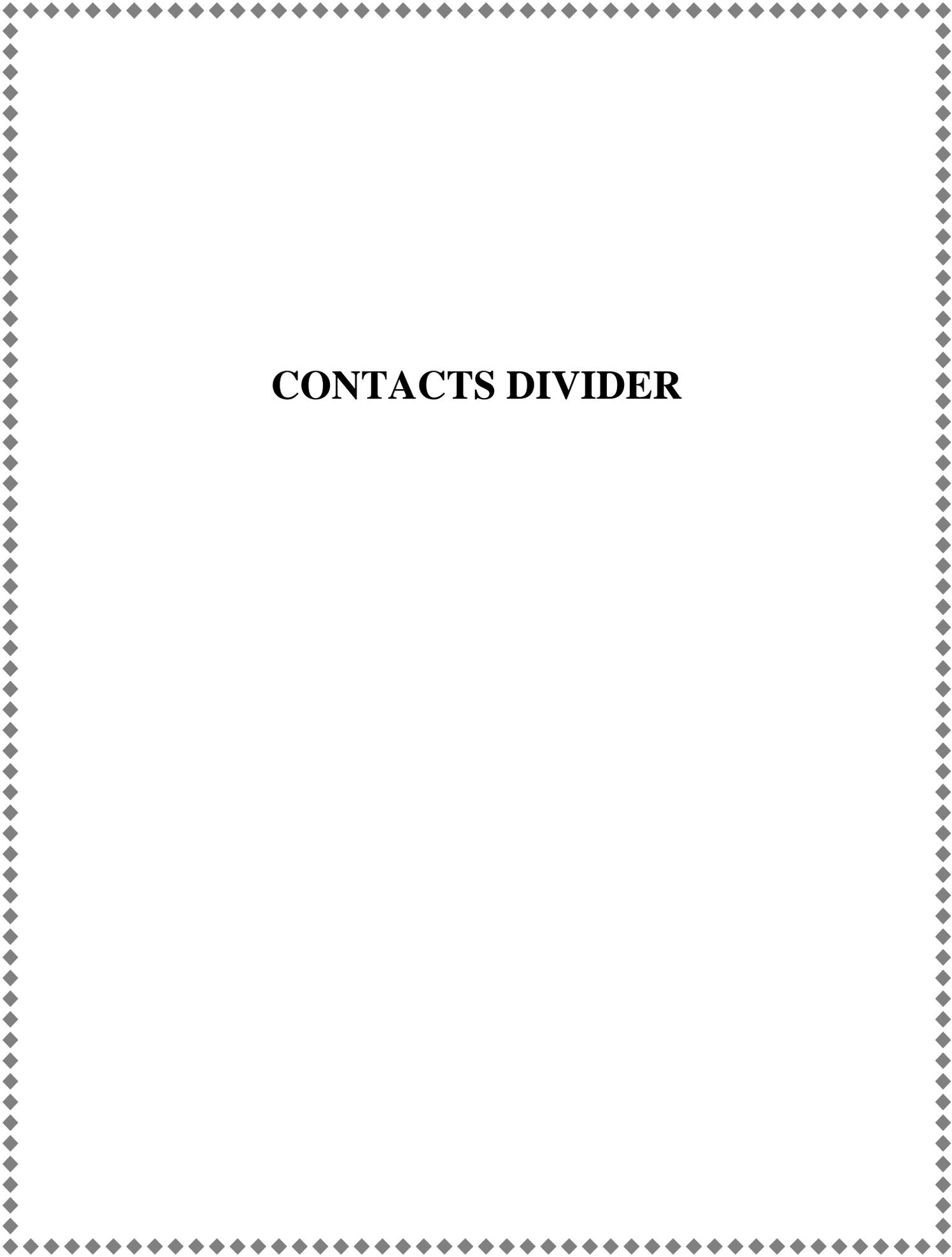












**CONTACTS DIVIDER**

Child's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

## Health Care Providers

**Tip:** Instead of filling out the form, staple your provider's business card onto the space provided.

### Primary Care Provider

Name \_\_\_\_\_ Specialty (if any) \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_ Telephone \_\_\_\_\_

Address \_\_\_\_\_

Fax \_\_\_\_\_ Email \_\_\_\_\_

### Medical Specialists and Health Care Providers

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Child's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

## Health Care Providers

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Name \_\_\_\_\_

Specialty \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Clinic/Hospital Name \_\_\_\_\_

Frequency of Visits (how often) \_\_\_\_\_

Child's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

## Health Insurance Plan

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### Primary Insurance

Name of Plan \_\_\_\_\_

Telephone \_\_\_\_\_

Address \_\_\_\_\_

Subscriber (Name of Policy Holder) \_\_\_\_\_

Subscriber ID# \_\_\_\_\_

Group # \_\_\_\_\_

Case Manager/Care Coordinator \_\_\_\_\_

Telephone \_\_\_\_\_

Other Contacts \_\_\_\_\_

Telephone \_\_\_\_\_

### Secondary Insurance

Name of Plan \_\_\_\_\_

Telephone \_\_\_\_\_

Address \_\_\_\_\_

Subscriber (Name of Policy Holder) \_\_\_\_\_

Subscriber ID# \_\_\_\_\_

Group # \_\_\_\_\_

Case Manager/Care Coordinator \_\_\_\_\_

Telephone \_\_\_\_\_

Other Contacts \_\_\_\_\_

Telephone \_\_\_\_\_

# Pharmacy

---

❖ Pharmacy: \_\_\_\_\_ Hours/Days of Operation: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Notes: \_\_\_\_\_

---

❖ Pharmacy: \_\_\_\_\_ Hours/Days of Operation: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Notes: \_\_\_\_\_

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❖ Pharmacy: \_\_\_\_\_ Hours/Days of Operation: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Notes: \_\_\_\_\_

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# Early Intervention Services

.....

❖ Developmental Center: \_\_\_\_\_  
Start Date: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Website/Email: \_\_\_\_\_

❖ Family Resources Coordinator: \_\_\_\_\_  
Start Date: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Website/Email: \_\_\_\_\_

# Therapists

.....

## Therapists:

❖ Occupational Therapist (OT) \_\_\_\_\_

Start Date: \_\_\_\_\_

Agency/Hospital/Clinic: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

❖ Physical Therapist (PT) \_\_\_\_\_

Start Date: \_\_\_\_\_

Agency/Hospital/Clinic: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

❖ Speech-Language Pathologist: \_\_\_\_\_

Start Date: \_\_\_\_\_

Agency/Hospital/Clinic: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

# Home Care



❖ Home Nursing Agency: \_\_\_\_\_

Start Date: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Website/Email: \_\_\_\_\_

❖ Home Nursing Agency: \_\_\_\_\_

Start Date: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Website/Email: \_\_\_\_\_

❖ Home Nursing Agency: \_\_\_\_\_

Start Date: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Website/Email: \_\_\_\_\_

# Child Care Community Health Care/Service Providers

.....

❖ Child Care Provider: \_\_\_\_\_

Start Date: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

❖ Child Care Provider: \_\_\_\_\_

Start Date: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

❖ Child Care Provider: \_\_\_\_\_

Start Date: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

# Respite Care Community Health Care/Service Providers

.....

❖ Respite Care Provider: \_\_\_\_\_  
Start Date: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Agency: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Website/Email: \_\_\_\_\_

❖ Respite Care Provider: \_\_\_\_\_  
Start Date: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Agency: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Website/Email: \_\_\_\_\_

❖ Respite Care Provider: \_\_\_\_\_  
Start Date: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Agency: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  
Website/Email: \_\_\_\_\_

# Public Health Community Health Care/Service Providers

.....

❖ Public Health Department: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

❖ Public Health Nurse: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

❖ Nutritionist: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

❖ Social Worker: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

❖ Other: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

# Family Support Resources

## Community Health Care/Service Providers

.....

❖ Support Group/Organization: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_

❖ Support Group/Organization: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_

❖ Religious Organization: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_

❖ Service Organization: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_

❖ Counseling Services: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_

# Family Support Resources

## Community Health Care/Service Providers



❖ Division of Developmental Disabilities: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_

❖ Other: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

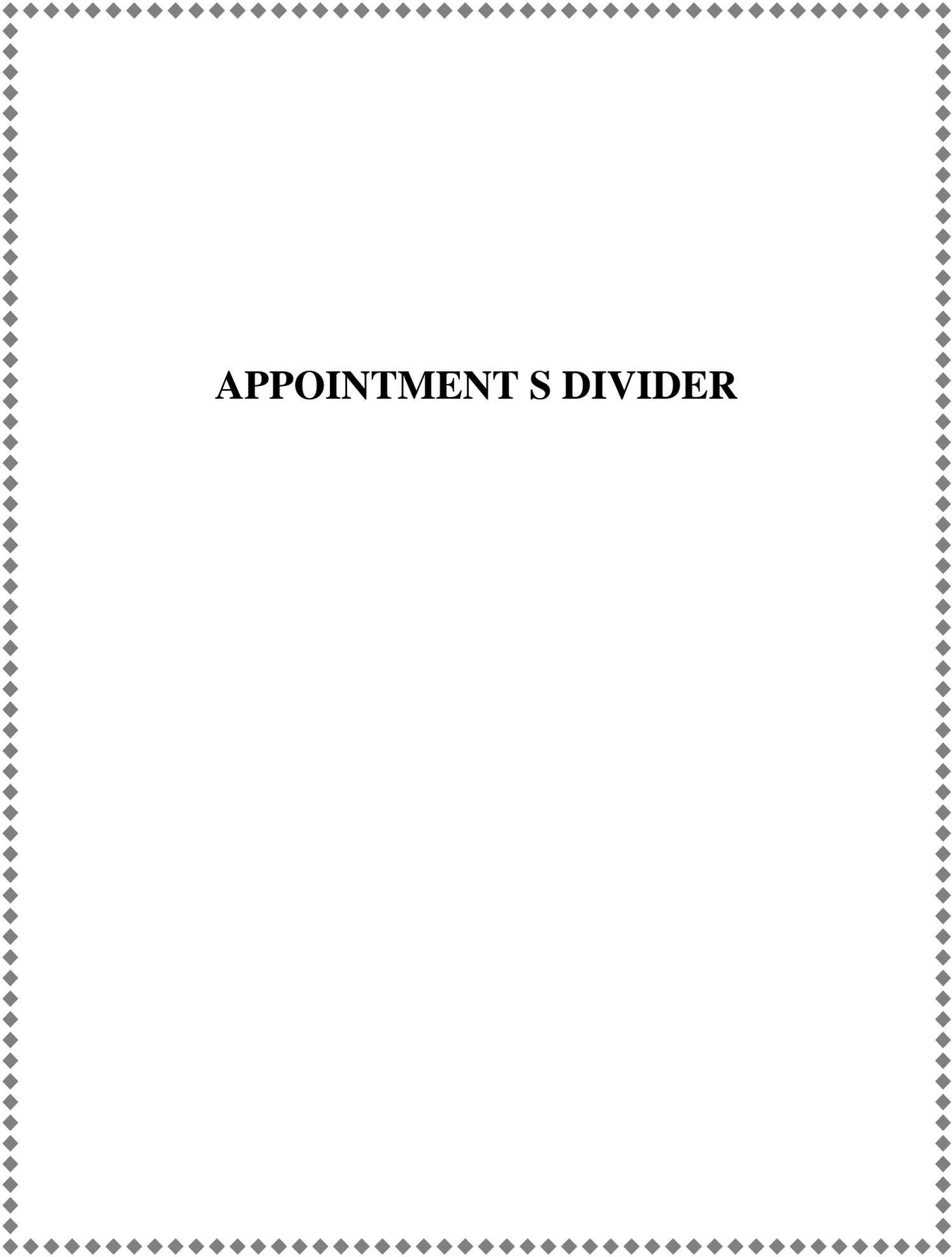
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_

❖ Other: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Website/Email: \_\_\_\_\_



**APPOINTMENT S DIVIDER**



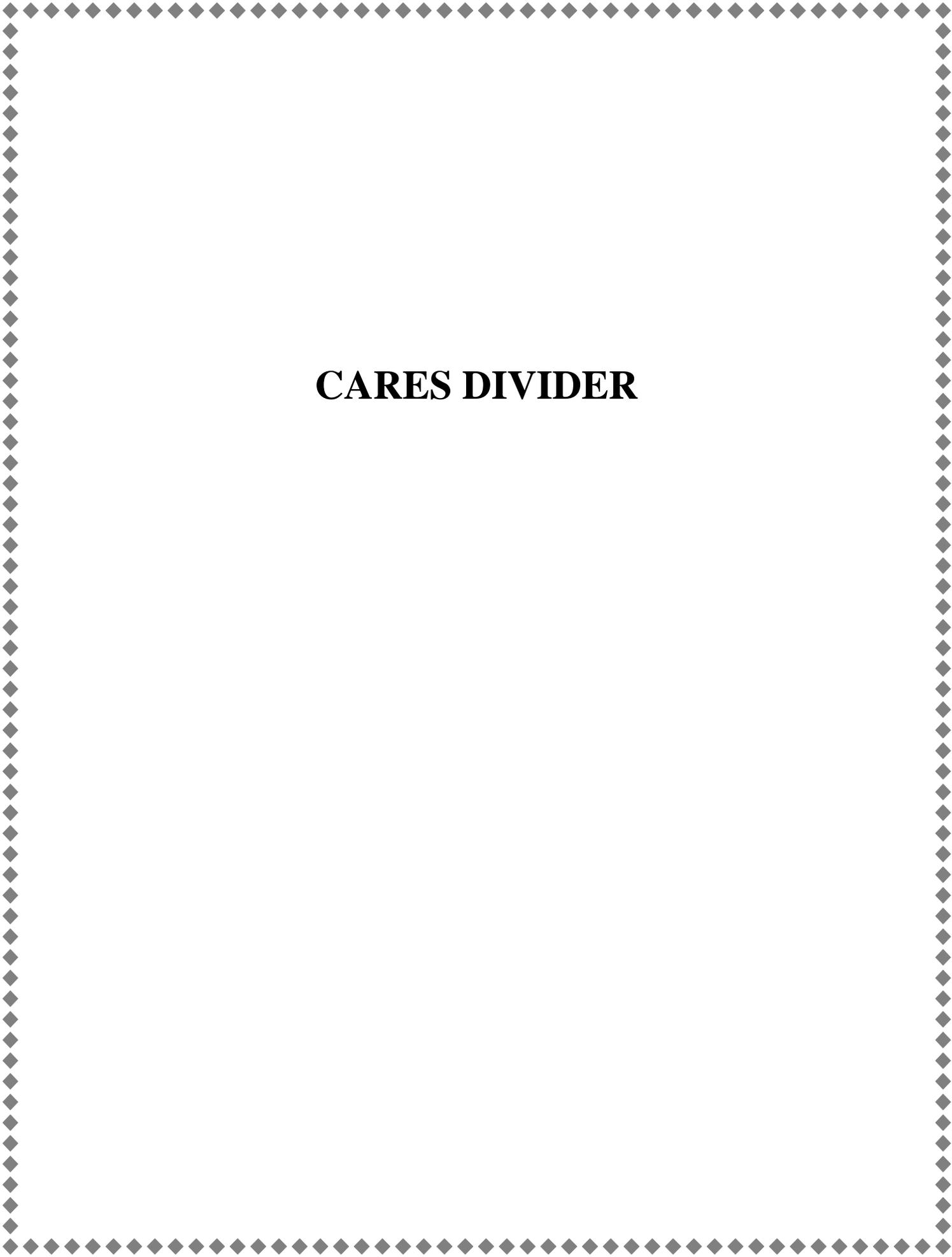












**CARES DIVIDER**



Child's Name \_\_\_\_\_

## BASELINE DATA

Normal Vital Signs:			
Pulse rate: _____ Site best taken: _____			
Blood pressure: _____ Site best taken: _____			
Temperature: _____ Site best taken: _____			
Respiratory Rate: _____ per minute      Oxygen Saturation: _____			
Pupils (normal, dilated, constricted, equal): _____			
Skin color: _____			
Blood draw site: _____			
Systems (Baseline Data)	OK ✓	Problem ✓	Comments/Description
CNS / Sensory			
Heart / Blood (include recent blood counts)			
Gastrointestinal			
Respiratory (describe breathing sounds)			
Genitourinary			
Musculoskeletal			
Baseline X-ray findings			
Developmental			
Communication			Does your child speak?    Yes    No Can s/he be understood by others?    Yes    No What language does your child speak? _____ Name of interpreter, if language other than English: _____
			Does your child use (Please circle all that apply): picture board    computer keyboard    sign language gesture/facial    other (specify) _____
			Is your child hearing impaired?    Yes    No
			Is your child legally blind?    Yes    No
Others:			



# My Child's Profile

Child's Name: \_\_\_\_\_ DOB: \_\_\_\_\_

Physician's Signature: \_\_\_\_\_

PROFILE / IX. IMMUNIZATIONS / ALLERGIES

## IX. Immunization and Allergy Record Log

Immunization:	Date	Date	Date	Date	Reaction if any	Physician
Diphtheria-Tetanus (DT)						
Diphtheria-Pertussis-Tetanus (DPT)						
Tetanus						
Polio (OPVIPV)						
Measles-Mumps-Rubella (MMR)						
Measles-Rubella (MR)						
Mumps						
Rubella (3-day Measles)						
Haemophilus Influenzae (HIB)						
Hepatitis A						
Hepatitis B						
Varicella (Chicken Pox)						
Rotavirus						
Pneumovoccal (Pneumovac)						
Pneumococcal Conjugate						
Influenzae (Flu Shot)						

Skin Test Log:			
Test	Date	Result	Provider
Newborn Screen			
Tuberculosis (TB)			



# Medications

. . . . .

Allergies:

Pharmacy:

Phone:

MEDICATION	DATE STARTED	DATE STOPPED	DOSE/ROUTE (with or without food?)	TIME GIVEN	PRESCRIBED BY

# Diet Tracking Form

.....

DATE	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

# Care Schedule

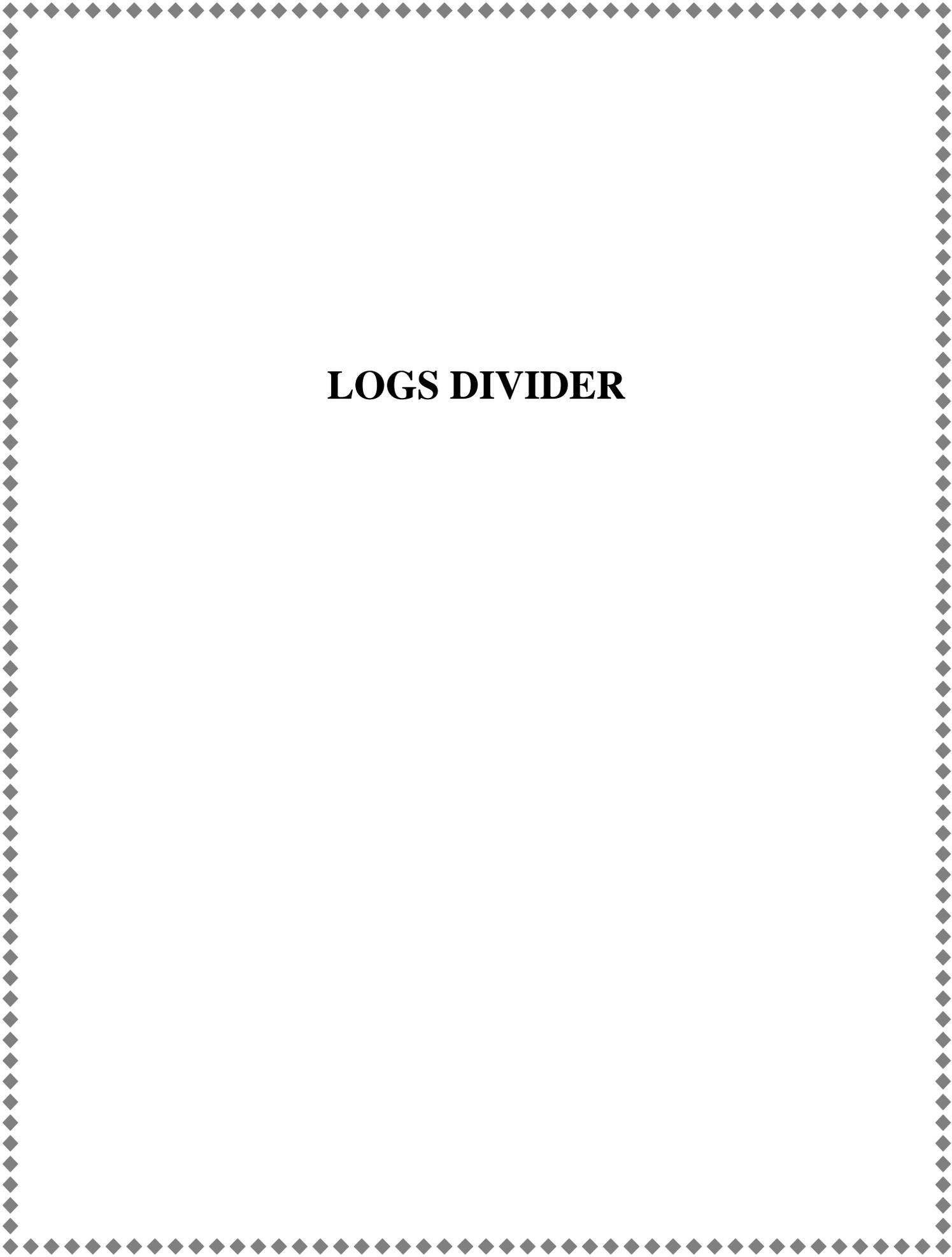


TIME	CARE
Morning	

# Care Schedule



TIME	CARE
Evening	



# **LOGS DIVIDER**











Child's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

## Supplies/Equipment

---

Description of Item \_\_\_\_\_

Provider/Vendor Name \_\_\_\_\_

Contact Person \_\_\_\_\_ Telephone \_\_\_\_\_

Prescribed by \_\_\_\_\_ Telephone \_\_\_\_\_

Reason Prescribed \_\_\_\_\_

Contact Person for Service/Insurance Approval \_\_\_\_\_

\_\_\_\_\_ Telephone \_\_\_\_\_

Comments (for example: kinds of service needed, part numbers, costs) \_\_\_\_\_

Description of Item \_\_\_\_\_

Provider/Vendor Name \_\_\_\_\_

Contact Person \_\_\_\_\_ Telephone \_\_\_\_\_

Prescribed by \_\_\_\_\_ Telephone \_\_\_\_\_

Reason Prescribed \_\_\_\_\_

Contact Person for Service/Insurance Approval \_\_\_\_\_

\_\_\_\_\_ Telephone \_\_\_\_\_

Comments (for example: kinds of service needed, part numbers, costs) \_\_\_\_\_

Description of Item \_\_\_\_\_

Provider/Vendor Name \_\_\_\_\_

Contact Person \_\_\_\_\_ Telephone \_\_\_\_\_

Prescribed by \_\_\_\_\_ Telephone \_\_\_\_\_

Reason Prescribed \_\_\_\_\_

Contact Person for Service/Insurance Approval \_\_\_\_\_

\_\_\_\_\_ Telephone \_\_\_\_\_

Comments (for example: kinds of service needed, part numbers, costs) \_\_\_\_\_

Child's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

## Supplies/Equipment

---

Description of Item \_\_\_\_\_

Provider/Vendor Name \_\_\_\_\_

Contact Person \_\_\_\_\_ Telephone \_\_\_\_\_

Prescribed by \_\_\_\_\_ Telephone \_\_\_\_\_

Reason Prescribed \_\_\_\_\_

Contact Person for Service/Insurance Approval \_\_\_\_\_

\_\_\_\_\_ Telephone \_\_\_\_\_

Comments (for example: kinds of service needed, part numbers, costs) \_\_\_\_\_

Description of Item \_\_\_\_\_

Provider/Vendor Name \_\_\_\_\_

Contact Person \_\_\_\_\_ Telephone \_\_\_\_\_

Prescribed by \_\_\_\_\_ Telephone \_\_\_\_\_

Reason Prescribed \_\_\_\_\_

Contact Person for Service/Insurance Approval \_\_\_\_\_

\_\_\_\_\_ Telephone \_\_\_\_\_

Comments (for example: kinds of service needed, part numbers, costs) \_\_\_\_\_

Description of Item \_\_\_\_\_

Provider/Vendor Name \_\_\_\_\_

Contact Person \_\_\_\_\_ Telephone \_\_\_\_\_

Prescribed by \_\_\_\_\_ Telephone \_\_\_\_\_

Reason Prescribed \_\_\_\_\_

Contact Person for Service/Insurance Approval \_\_\_\_\_

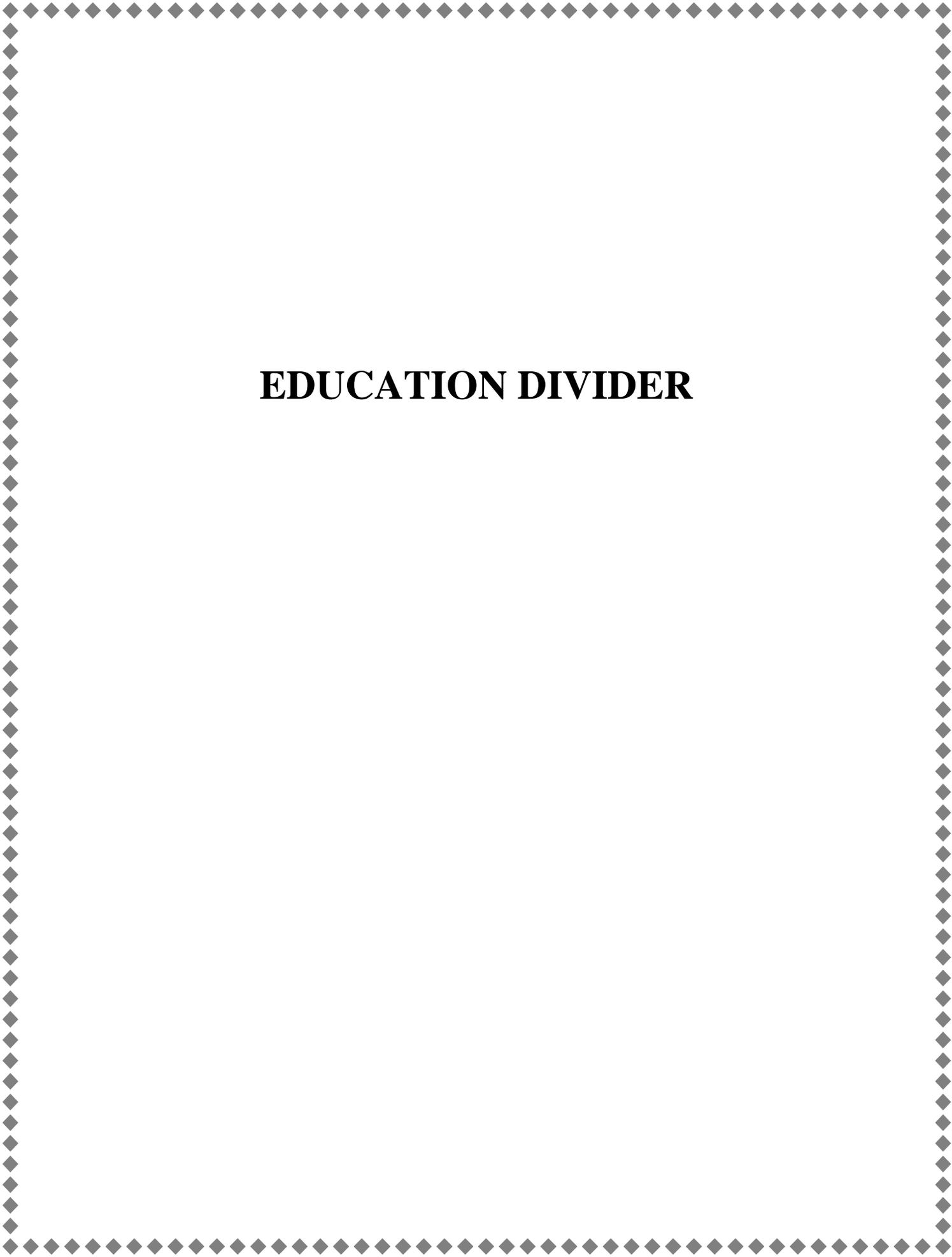
\_\_\_\_\_ Telephone \_\_\_\_\_

Comments (for example: kinds of service needed, part numbers, costs) \_\_\_\_\_









**EDUCATION DIVIDER**

## **My child has a chronic health condition. What do I need to tell the school?**

If your child has special health needs, the school should have a written health care and emergency plan. The health care plan should include:

- Correct emergency contact information
- A brief medical history
- The child's special needs
- Medicine or special care required during the school day
- Special dietary needs
- Transportation needs
- Possible problems, special precautions
- Pediatrician's name
- Emergency plans and procedures (including whom to contact)

Once the school knows a student has a chronic health condition, a meeting is often held to discuss what services may be needed. The meeting should include parents, the student (if old enough), school health staff, the coordinator of special needs services, student aids, and the child's primary teacher. Health care providers, such as the child's pediatrician, also should be invited in person or by phone or asked to provide information in writing.

One goal of this meeting is to develop a written plan that clearly describes the services the student needs. Depending on the child's needs, this plan may be described as a 504 Plan or an Individualized Education Program (IEP). This legal document states exactly what services the child will receive and sets short and long term goals for the child. The plan should be reviewed regularly to make sure it continues to meet the child's needs.

### **Parent Responsibilities**

Here are ways you can help your child receive what he or she needs to succeed in school:

- **Talk to the school.** Don't be afraid to tell the school about your child's condition. Some parents worry about sharing this information, but the more informed teachers and other school staff are, the better prepared they will be to help your child. If the school staff don't have all the facts, they may make wrong assumptions about your child's behavior or performance.
- **Make an emergency plan.** Ask your pediatrician to help you write down exactly what the school should do if certain events (such as pain, wheezing or seizures) are likely to happen at school. School staff should know how to reach you or your pediatrician in case there is an emergency. Remember to call the school right away when contact information has changed.
- **Make a health plan.** If your child takes medicine at school, ask about the school's policies for storing medicine in school and for children taking their own medicine if they are capable. Make sure your child is able to take her medicine in

a comfortable place, and that the school is provided with an adequate supply. Remember to call the school right away if there are any changes in your child's medication.

- **Give your consent.** You will have to sign a release form to give the school permission to contact your pediatrician. Also, your pediatrician will need your written permission to discuss your child's condition with the school. If your child requires medicine or special procedures, the school must receive written instructions from your pediatrician.
- **Plan ahead.** Contact your child's teachers regularly to talk about how your child is doing at school. Ask if your child's health condition is affecting her schoolwork or behavior. If your child is missing a lot of school due to illness, talk with her teacher about ways to help her keep up with her work.

## **Know the Law**

By law, your child is entitled to an education that will help her develop to her full potential. Schools may be required to provide additional services that will assist in both in-school programs and after-school events. Federal laws such as the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) state that every child should be allowed to attend school in the "least restrictive" setting possible.

**Source: Adapted from Students With Chronic Health Conditions: Guidance for Families, Schools, and Students (Copyright 2004 American Academy of Pediatrics)**

# School Contacts

(Some parents store IEP and 504 plan information in sheet protectors following this section.)

---

☼ School District: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Web Site: \_\_\_\_\_

Special Education Coordinator: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

504 Accommodation Plan Coordinator (if different from above): \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

District Nurse assigned to your child's school: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

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☼ School / Preschool: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Web Site: \_\_\_\_\_

Principal / Administrator: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Classroom Teacher: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Resource Instructor: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Aide / Assistant / Intervener: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Special Education Director / Teacher(s): \_\_\_\_\_

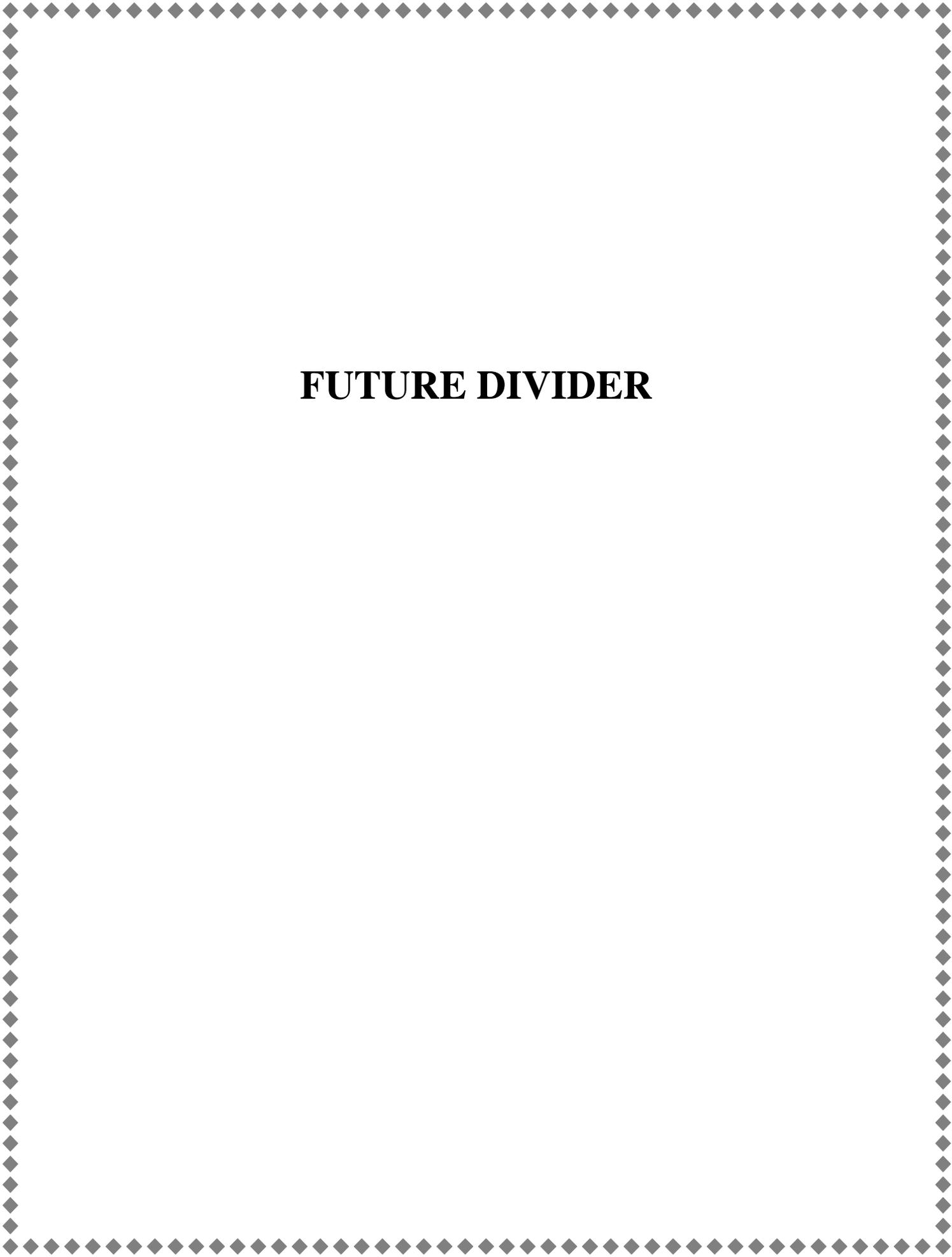
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Therapist(s): \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Other Contacts: \_\_\_\_\_

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**FUTURE DIVIDER**

## *Ten Steps to Health Care Transition*

How families can help their child with special health care needs plan the move from child-centered to adult-centered health care systems.

- 1. Start Early!** There are some things you can do to get ready for transition even when your child is very young, like starting to keep a medical summary and teaching your child about his or her health care needs.
- 2. Create a medical summary.** Put all of the important information about your child's health care in one place, including plans for an emergency.
- 3. Create a health care transition plan.** Work on a written health care transition plan with your child's primary care doctor. Start this plan by the time your child is 14 years old. Review and update the plan at least once a year.
- 4. Focus on responsibility for health care.** Help your child understand and take responsibility for his or her health care based on age and abilities. Find out what your child knows about his or her health care needs and fill in the gaps.
- 5. Consider the need for additional supports.** Some young people will be unable to make informed decisions about their health care in adulthood due to illness, mental illness, or a developmental disability. In Maryland, the Health Care Decisions Act allows a family member or close friend to act as a surrogate to make most medical decisions for someone in this situation without requiring legal guardianship.
- 6. Maintain wellness.** Encourage a healthy lifestyle. Help your child start good habits that will continue into adulthood.
- 7. Know your child's health insurance options.** It is important to find out what types of private or public insurance your child will be eligible for as an adult. If you have already chosen health care providers who work with adults, check to see if these providers are in the plan.
- 8. Find new providers.** Pick a primary care doctor (and specialist if needed) who works with adults. You can ask your child's current providers for a referral. Ask local support groups or other families that you know to recommend a doctor. Ask your child's current providers to speak with the doctor you have selected.
- 9. Include health in other areas of transition.** Find out how your child's special health care needs may impact his or her future and other areas of life such as independent living, work, and relationships. Consider whether accommodations will be needed in the home, workplace, etc. Ask your child's primary care physician to provide documentation of his or her medical conditions and special health care needs for other programs or agencies as needed.
- 10. Celebrate moving on.** Transition can be an emotional process. You may not want to say goodbye to a doctor who has taken good care of your child and family for many years. Remember that transition is a part of growing up, and all young people deserve the right to take on adult roles to the best of their abilities.

## ***TRANSITION RESOURCES***

1. Office for Genetics and Children with Special Health Care Needs, Department of Health and Mental Hygiene: <http://fha.maryland.gov/genetics/> or call 410-767-5298.
2. The Center for Children with Special Needs– Teen Transition:  
<http://cshcn.org/teen-transition-adult-health-care> or call 1-866-987-2500.
3. National Center for Medical Home Implementation – Building your Care Notebook:  
[http://www.medicalhomeinfo.org/for\\_families/care\\_notebook/](http://www.medicalhomeinfo.org/for_families/care_notebook/) or call 1-800-433-9016 ext. 7605.
4. Healthy and Ready to Work: [http://www.syntiro.org/hrtw/tools/check\\_care.html](http://www.syntiro.org/hrtw/tools/check_care.html)
5. Maryland Transitioning Youth: <http://www.mdtransition.org/Health%20Care.htm>
6. Maryland State Department of Education, Division of Rehabilitation Services:  
<http://www.dors.state.md.us/dors> or call 410-554-9442.

## Got Health Care? Check Your Skills

(Maryland Office for Genetics and Special Health Care Needs. Form more information visit: [http://fha.maryland.gov/genetics/healthcare\\_transition.cfm](http://fha.maryland.gov/genetics/healthcare_transition.cfm))

### AGES 12 – 14 “New Responsibilities”

#### Transition Checklist

*(Check the items that are true for you.)*

- I can describe how my disability or health condition affects my daily life.
- I can name my medications (using their proper names), and the amount and times I take them.
- I answer at least one question during a health care visit.
- I have talked with my doctors or nurses about going to different doctors when I am an adult.
- I manage my regular medical tasks at school.
- I can call my primary care doctor's or specialist's office to make or change an appointment.

### AGES 15 – 17 “Practicing Independence”

#### Transition Checklist

*(Check the items that are true for you.)*

- I keep a personal health notebook or medical journal.
- I reorder my medications when my supply is low and call my doctor when I need a new prescription.
- I answer many of the questions during a health care visit.
- I spend most of the time alone with the doctor(s) during health care visits.
- I tell my doctors I understand and agree with the medicines and treatments they suggest.
- I know if my doctors do not take care of patients who are older than a certain age (for example, 21).
- I regularly do chores at home.
- I can tell someone the difference between a primary care doctor and a specialist.

### AGES 18 & UP “Taking Charge”

#### Transition Checklist

- I can tell someone the effects that getting older may have on my disability or health condition.
- I can tell someone about medications that I should not take because they might interact with the medications I take.
- I am alone with the doctor(s) or choose who is with me during health care visits.
- I answer all the questions during a health care visit.
- I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
- I manage all of my regular medical tasks outside the home (school, work).
- I can tell someone what new legal rights and responsibilities I gained when I turned 18 years old (sign medical consent forms, make medical decisions by myself).
- I can tell someone how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (such as be a full-time student).

## Got Health Care? Parent's Health Care Check List for Transitioning Youth

(Maryland Office for Genetics and Special Health Care Needs. Form more information visit:  
[http://fha.maryland.gov/genetics/healthcare\\_transition.cfm](http://fha.maryland.gov/genetics/healthcare_transition.cfm))

QUESTION	YES	NOT YET	FIRST STEPS
Do I know how my teen learns best?			
Can my teen describe his/her special health care needs?			
Do we discuss and demonstrate healthy lifestyle habits as a family?			
Can my teen name his/her doctor?			
Can my teen communicate that he/she is feeling ill?			
Can my teen describe symptoms when feeling ill?			
Do we use a family calendar for tracking appointments, activities, etc.?			
Is my teen involved when I schedule appointments?			
Can my teen schedule appointments on his/her own?			
Do I encourage my teen to give information and answer questions at appointments?			
Have I discussed transitioning to adult care providers with my teen's present providers?			
Do I involve my teen in registering or checking in for appointments (showing insurance/MA card)?			
Does my teen know the medications he/she is taking, the reason, schedule and pertinent side effects?			
Do I involve my teen in filling and refilling prescriptions?			

Source: *Transition to Adult Health Care: A Training Guide in Two Parts* from Waisman Center, University of Wisconsin-Madison, University Center for Excellence in Developmental Disabilities. Available at:  
<http://www.waisman.wisc.edu/wrc/pdf/pubs/TAHC.pdf>

## Got Health Care? Parent's Health Care Check List for Transitioning Youth

(Maryland Office for Genetics and Special Health Care Needs. Form more information visit:  
[http://fha.maryland.gov/genetics/healthcare\\_transition.cfm](http://fha.maryland.gov/genetics/healthcare_transition.cfm))

QUESTION	YES	NOT YET	FIRST STEPS
Is my teen involved in maintaining/ordering monthly supplies, equipment or scheduling home care?			
If my teen is on my insurance, do I know how long this can continue?			
Do I know what insurance or health care coverage will be available to my teen when he/she turns 18?			
Have we talked about and made plans for guardianship (none, full, limited)?			
Have we discussed and planned for Power of Attorney for Health Care?			
Do I use formal and/or informal advocacy or supports and is my teen aware of this?			

Source: *Transition to Adult Health Care: A Training Guide in Two Parts* from Waisman Center, University of Wisconsin-Madison, University Center for Excellence in Developmental Disabilities. Available at:  
<http://www.waisman.wisc.edu/wrc/pdf/pubs/TAHC.pdf>





# Estate/Future Planning

Developed by The Center for Infants and Children with Special Needs: Children's Hospital Medical Center of Cincinnati and The Arc of Hamilton County.

## Letter of Intent

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 own thoughts and getting them down on paper. You can begin with the less emotional section like the Personal Information before moving on to the more 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. Update the plan annually; birthdays are a good time to do this. Don't forget to 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.

Parent/Caregiver Signature\_\_\_\_\_

Date\_\_\_\_\_

Parent/Caregiver Signature\_\_\_\_\_

Date\_\_\_\_\_

## Family Information

Mother's Name \_\_\_\_\_

Maiden Name \_\_\_\_\_

Social Security Number \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Father's Name \_\_\_\_\_

Social Security Number \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Sibling(s)

Name \_\_\_\_\_

Spouse \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Name \_\_\_\_\_

Spouse \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Name \_\_\_\_\_

Spouse \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Name \_\_\_\_\_

Spouse \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Name \_\_\_\_\_

Spouse \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

**NAMES AND ADDRESSES OF OTHER RELATIVES**

And whether they have been notified that you have established a Trust so that if they want to leave money to your child/sibling, to leave it to the Trust.

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone Number \_\_\_\_\_  
Notified  yes  no    Date notified \_\_\_\_\_

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone Number \_\_\_\_\_  
Notified  yes  no    Date notified \_\_\_\_\_

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone Number \_\_\_\_\_  
Notified  yes  no    Date notified \_\_\_\_\_

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone Number \_\_\_\_\_  
Notified  yes  no    Date notified \_\_\_\_\_

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone Number \_\_\_\_\_  
Notified  yes  no    Date notified \_\_\_\_\_

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone Number \_\_\_\_\_  
Notified  yes  no    Date notified \_\_\_\_\_

List of individuals, advocates and/or service providers who touch the life of my child/sibling.

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

What they typically do with/for my child/sibling

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Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

What they typically do with/for my child/sibling

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---

---

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

What they typically do with/for my child/sibling

---

---

---

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

What they typically do with/for my child/sibling

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## 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?

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

Home Manager

Name and Phone Number \_\_\_\_\_

Case Manager

Name and Phone Number \_\_\_\_\_

First Choice of Future Residential Provider

\_\_\_\_\_

Second Choice \_\_\_\_\_

Other Service Agencies

(Example: Family Resources, Transportation, etc.)

Agency Name \_\_\_\_\_

Contact Person \_\_\_\_\_

Phone Number \_\_\_\_\_

Reason Used \_\_\_\_\_

Agency Name \_\_\_\_\_

Contact Person \_\_\_\_\_

Phone Number \_\_\_\_\_

Reason Used \_\_\_\_\_

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)

\_\_\_\_\_

BANK\_\_\_\_\_ Branch Location\_\_\_\_\_

Checking Account Number\_\_\_\_\_

Safe Deposit box\_\_\_\_\_

Savings Account Number\_\_\_\_\_

LIFE INSURANCE

Company\_\_\_\_\_

Policy number\_\_\_\_\_

BURIAL POLICY

Funeral Home\_\_\_\_\_

Cemetery\_\_\_\_\_

Will and Estate Plans

Letters of Guardianship have been approved by:

Judge \_\_\_\_\_ Date \_\_\_\_\_

Approved Guardian's Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Relationship \_\_\_\_\_

Approved Successor Guardians

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Relationship \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Relationship \_\_\_\_\_

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

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## TRUSTS

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

Several different trust options are now available that allow provision for people with disabilities without affecting their eligibility for Medicaid and SSI. In general, these trusts cannot be used to pay for support and care (necessities of life) without jeopardizing an individual's eligibility for Medicaid and SSI. It is also worth remembering that it does not take a great deal of money to pay only for supplemental items or luxuries. Thus, the trust doesn't need to have a great deal of money in it to accomplish its purpose." From Estate and Future Planning: Handbook for Ohioans with Disabilities and Their Families," David A Zwyer, Esq, 2004.

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Attorney/Agency/Company managing the trust

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Address

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Phone Number

Location of a copy of the Trust\_\_\_\_\_

List agencies notified about the Trust\_\_\_\_\_

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## LAST WILL AND TESTAMENT

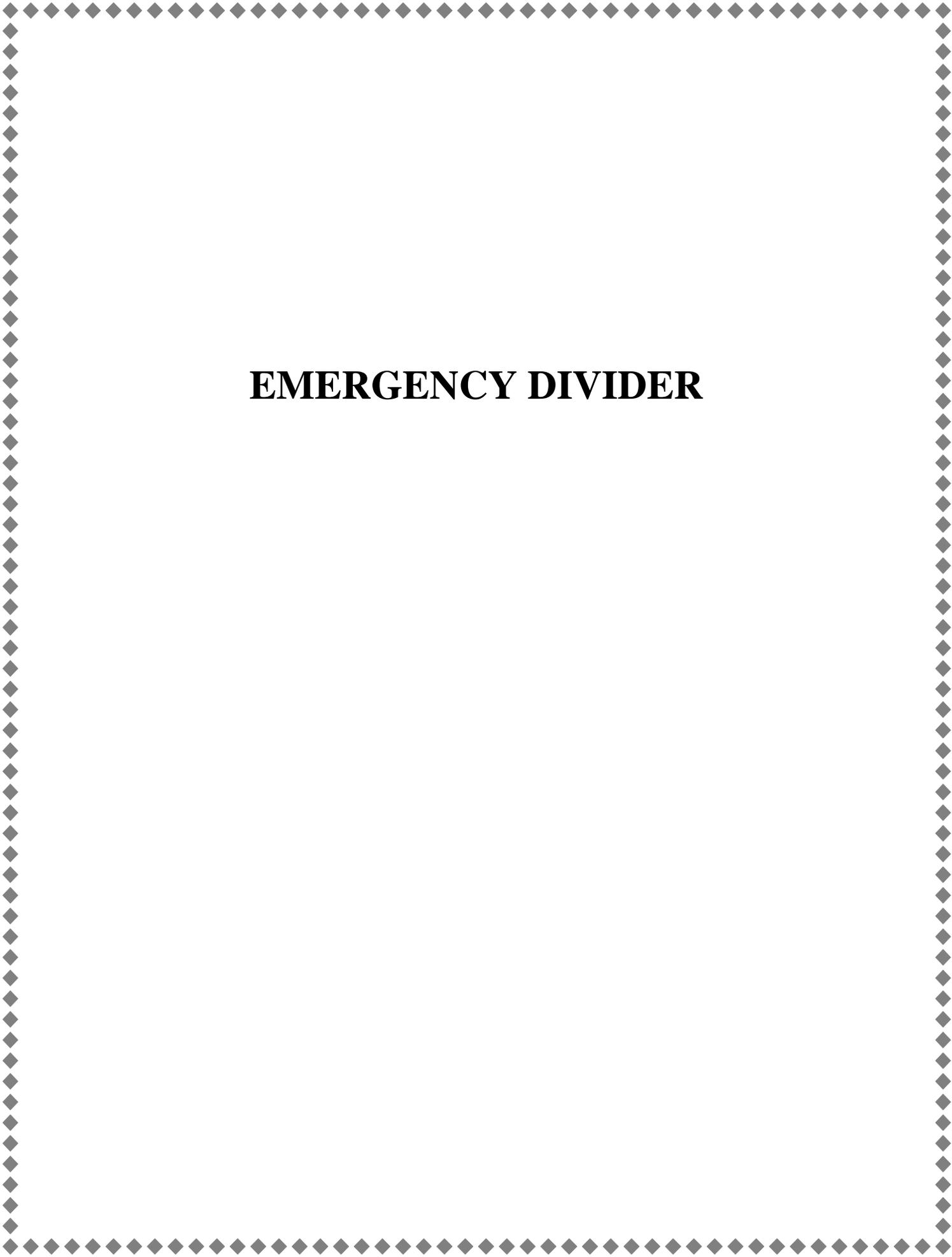
"A document that might be used to more fully explain the intent of a person making a Will is called a Letter of Instruction. It may make sense to more fully express one's wishes in such a Letter of Instruction than is really proper for a legal instrument such as a Will."

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

Attorney \_\_\_\_\_

Location of a copy of the Will \_\_\_\_\_

<sup>1</sup>Durable Power of Attorney \_\_\_\_\_



**EMERGENCY DIVIDER**

## ***Emergency Preparedness for Children with Special Needs***

Adapted from Seattle Children's Hospital, The Center for Children with Special Health Care Needs: <http://cshcn.org/planning-record-keeping/emergency-preparedness-children-special-needs>

Preparing for an emergency is difficult for any parent, and as a parent caring for a child with special needs, you have extra things to think about.

Try to reflect on your child's needs if there was:

- \*No water, electricity, telephone, heat, air conditioning, or refrigeration.
- \*No local access to prescription refills or health products.
- \*Separation from family members.
- \*Confinement to home or evacuation to a shelter or elsewhere.
- \*Limited health care access and emergency rescue services.
- \*A lack of transportation.

Here are a few tools to help you be prepared, in case of an emergency:

- \*[Create an emergency plan](#)
- \*[Pack an emergency supply kit](#)
- \*[Find other emergency preparedness information](#)

*We wish to thank the Washington Family to Family Health Information Center and the American Red Cross-Seattle Chapter for assistance with this information.*

### **Create an Emergency Plan**

The first step to creating an emergency plan is to sit down and talk with your family about different types of emergencies, how to prepare for them, and brainstorm ideas of how to care for your child with special needs during an emergency.

You should also discuss how to care for your child during different types of emergencies with your child's doctor or health care team. Be sure to develop a plan for how you will communicate with your child's care team during an emergency.

Learn about emergency plans at your child's school or child care center. Learn their plans for shelter-in-place emergencies and how your child will get treatment, medications etc. Be sure to get their emergency contact numbers.

## **Ways to plan**

- \* Plan for back up sources of heat, refrigeration, and electricity: Your family can use an emergency shelter for storing medicine, charging equipment, help with medical needs, getting a meal and more. You do not have to be staying in a shelter to use its resources.
- \* If your child depends on dialysis or other life sustaining treatment, know the location of more than one facility: find out the facility's plans for emergencies and how your child will get treatment, medications, etc. Get their emergency contact numbers (these may be out of state).
- \* Create and practice an escape plan for your home: be sure there are clear exit paths for a child who uses mobility devices or has vision loss and keep a pair of shoes stored under the bed of each family member in case of evacuation.
- \* Talk to your local police and fire departments to see if they have emergency services or plans for people with special needs.
- \* Plan for your child's service animal.
- \* Obtain a medical alert and/or identification bracelet for your child.
- \* Know where to tune to your local emergency radio station, in the event of a large scale disaster.
- \* Plan for and get supplies for natural disasters that may be in your area: Pack an emergency supply kit and store extra medicines and equipment at your child's school.

## **Create a support network**

Once you have created an emergency plan, it is helpful to have some back-up. Your support network may include family, neighbors, or friends that can help you and your child.

- \* Tell your support network about your child's special needs and share your emergency plan and where your emergency supplies are stored.
- \* Give a trusted member of your network a key to your house or apartment.
- \* Agree upon a system with your network to signal for help if phones and electricity are not working.
- \* Show others how to handle your child's wheelchair or other equipment.
- \* Talk to other families who have a child with the same condition as your child about ideas and tips.

## **Pack an Emergency Supply Kit**

In addition to supplies needed for a general disaster kit, you may need to add several things to the kit for your child with special needs.

## **General Information and Supplies:**

- \* A copy of your child's up to date Care Plan , including the In Case of Emergency Form.
- \* Current medical information and records stored on a CD, flash drive, or phone app (keep one paper copy in a waterproof bag).

- \* If needed: extra contact lenses, glasses, and lens supplies; batteries for hearing aids and communication devices; Special dietary foods and supplies.
- \* Items that calm or entertain your child.
- \* Identification to be carried by each child in case your family gets separated.
- \* Proof of service animal status to insure a service animal can go with you into a shelter.

### **Power Supplies:**

- \* A generator for back up power support (due to deadly fumes, *never* use a generator indoors).
- \* An AC adaptor for your car for small electrical equipment such as a nebulizer.
- \* A way to charge your cell phone without electricity.
- \* Battery powered versions of medical equipment your child uses
- \* Manual wheelchair or other non-electric equipment.

### **Medical Supplies and Medications:**

Talk with your child's doctor about how to obtain an extra supply of medicines for emergencies. Ask if it would be safe to change a dosage in an emergency situation. If your child takes medicine administered by a clinic or hospital, talk with them about how to plan for a 3-14 day disruption. Ask your pharmacist about the shelf life and storage needs of the medicines.

- \* Two-week supply of medical items including syringes, dressings, nasal cannulas, suction catheters, etc.
- \* At least a three day supply of medications (fourteen days is ideal).
- \* Cooler and chemical ice packs for storing medications that must be kept cold.
- \* Prescription information for your wallet, survival kit, and car that includes the name, location and phone number of an out of town pharmacy.

### **Other Helpful Tips:**

- \* Pack a smaller "to go" kits for use in an evacuation and store in multiple places (car, work, school, etc.).
- \* Store your supplies in an easy-to-get-to waterproof and pest-proof container.
- \* Update supplies yearly, replace water every six months, and update emergency contact and medical forms as needed.
- \* If you can't contact your doctor or pharmacy in a disaster, ask for help from emergency responders or staff at emergency shelters or service centers. You can get help in getting medication from a Red Cross shelter.

## Emergency Preparedness Resource List

### Special Needs Emergency Preparedness Information

\* *Disability Resource Center:*

<http://www.disabilitypreparedness.gov/ppp/disabil.htm> Emergency preparedness for special needs including disability specific tips.

\* *Keeping Children and Youth with Special Health Care Needs Safe During*

*Emergencies and Disasters:* <http://www.familyvoices.org/work/caring?id=0004>  
content from Family Voices on how to make an emergency plan for your child with special health care needs.

\* *Department of Homeland Security:* <http://www.ready.gov/individuals-access>

[functional-needs](http://www.ready.gov/individuals-access) Emergency preparedness for individuals with disabilities and special needs.

\* *American Red Cross Information for People with Disabilities:*

[http://www.redcross.org/museum/prepare\\_org/disabilities/disabilitiesprep.htm](http://www.redcross.org/museum/prepare_org/disabilities/disabilitiesprep.htm)  
information designed to assist people with disabilities and medical concerns to prepare for disasters.

\* *Maryland Emergency Management Agency:*

[http://www.mema.state.md.us/MEMA/content\\_page.jsp?TOPICID=specialNeeds](http://www.mema.state.md.us/MEMA/content_page.jsp?TOPICID=specialNeeds)  
Emergency information for persons with disabilities in Maryland

\* *Maryland Department of Disabilities:*

<http://www.mdod.state.md.us/Emergency%20Preparedness%20Home.aspx>  
More information on emergency preparedness for Marylanders.

\* *Disability specific tips for people with:*

**-Mobility Challenges**

<http://www.seattle.gov/emergency/docs/Prepare%20if%20I%20have%20mobility%20challenges.pdf>

**-Hearing Impairment**

<http://www.seattle.gov/emergency/docs/Prepare%20for%20Hearing%20Impaired.pdf>

**-Visual Disabilities**

<http://www.seattle.gov/emergency/docs/prepare%20if%20I'm%20visually%20impaired.pdf>

**-Special Medical Needs**

<http://www.seattle.gov/emergency/docs/Prepare%20with%20Medical%20Needs.pdf>

**-Hemophilia**

<http://www.hemophilia.org/NHFWeb/Resource/StaticPages/menu0/menu8/menu125/AtAGlanceIndividual.pdf>

### General Emergency Preparedness Information

\* *Department of Homeland Security Ready Site:* <http://www.ready.gov/> Information for parents on how to prepare, plan, and stay informed in an emergency. Also has an interactive games section for kids.

\**FEMA Site*: <http://www.fema.gov/> Links for both parents and children from the Federal Emergency Management Agency of the Department of Homeland Security.

\**American Red Cross Site*: <http://www.redcross.org/> Disaster services and preparedness information.

### **Helping Children Cope with Disaster**

\**Helping Children Cope with Disaster* :

<http://www.cert-la.com/education/HelpingChildrenCopeWithDisaster.pdf> Includes how children react to disaster by age, meeting your child's emotional needs and teaching your children how to call 911.

\**How to Help Children After a Disaster*:

<http://www.seattle.gov/emergency/docs/Prepare%20Children.pdf>

Things parents can do to help their children, behaviors children may show after a disaster, and more.

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