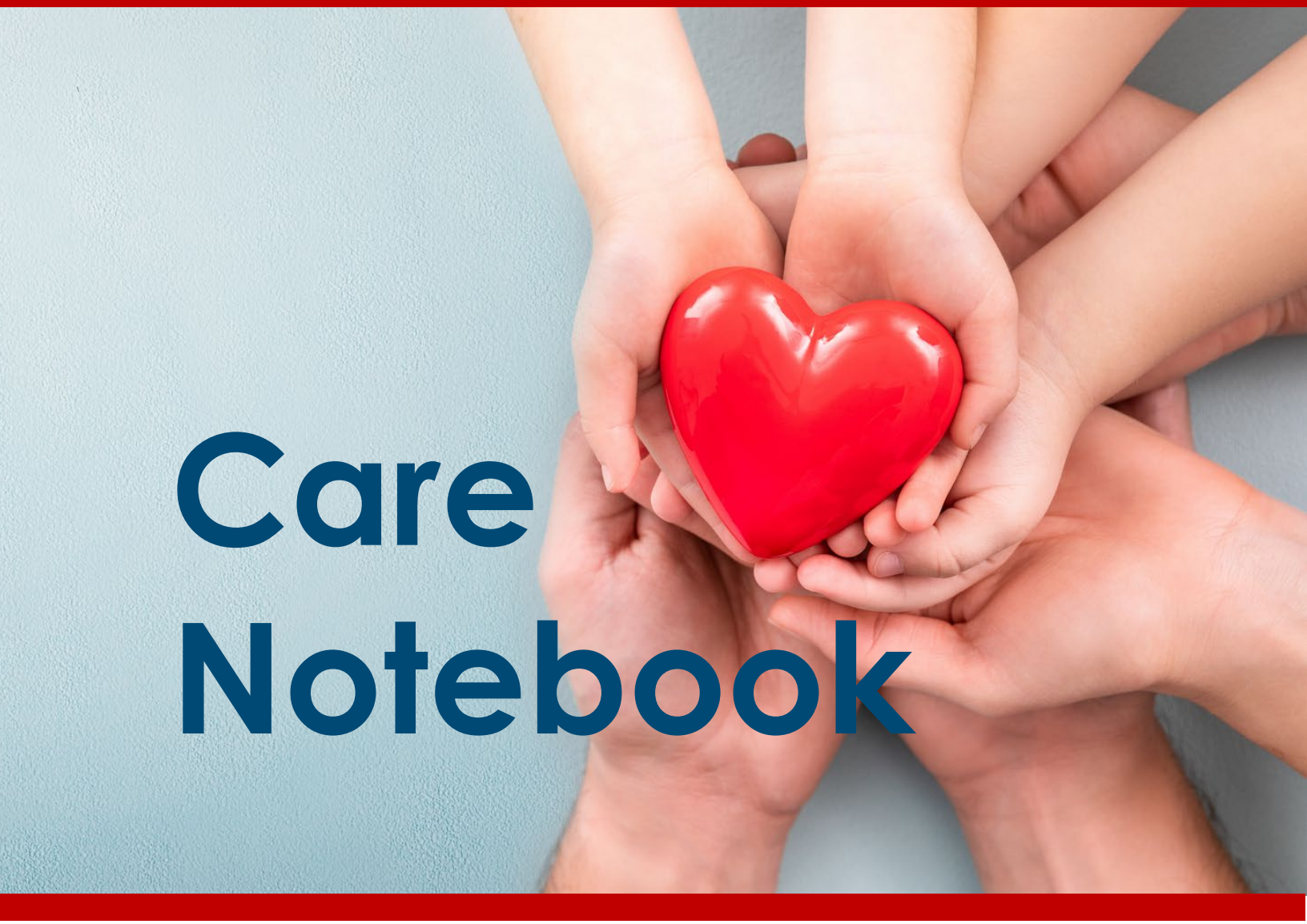


Care Notebook

FAMILY VOICES OF NORTH DAKOTA®

Navigating Crossroads to Hope

Introduction

The Care Notebook is available for download, or you can create your personalized book by choosing just pages you need. The PDF forms are fillable, so you can enter your child's information on a computer or smartphone if you wish and save it online, or you can print out the pages and enter your child's information by hand. If you do not have access to a printer please contact Family Voices of North Dakota, contact information below.

You will need the free Adobe Reader on your device to open and view the PDF documents. This format allows you to save files that cannot be modified but can be easily shared and printed. You can download a desktop version of Adobe Acrobat Reader at https://acrobat.adobe.com/us/en/acrobat/pdf-reader.html#tt or look for Adobe Acrobat Reader in the App Store or Google Play Store.

Please accept this copy of the Family Voices of North Dakota (FVND) Care Notebook.

This is your copy from FVND feel free to copy pages and use as it fits your child's needs.

Please direct any comments, suggestions, or questions to:

Donene Feist, Director
fvnd@drtel.net
888-522-9654
FAX: 701-493-2635
Family Voices of North Dakota
P.O. Box 163
Edgeley, ND 58433

FVND Care Notebook: A Quick Guide

What is a Care Notebook?

A Care Notebook is an organizing tool for families who have children with special health care needs or disabilities. Use a Care Notebook to keep track of important information about your child's health care all in one place. This is available online in fillable PDF forms that you can complete on a computer and save electronically or download and print and complete by hand.

How can a Care Notebook help me?

In caring for your child with special health care needs and/or disabilities, you may get information and paperwork from many sources. A Care Notebook helps you organize the most important information in a central place. A Care Notebook makes it easier for you to find and share key information with others who are part of your child's care team.

Use your Care Notebook to:

- Track changes in your child's medicines or treatments
- List telephone numbers for health care providers and community organizations
- Prepare for appointments
- File information about your child's health history
- Share new information with your child's primary provider, public health or school nurse, daycare staff, and others caring for your child

What are some helpful hints for using my child's Care Notebook?

Store the Care Notebook where it is easy to find. This helps you and anyone who needs information when you are not there. Add new information to the Care Notebook whenever your child's treatment changes. Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be easy to find.

Setting Up the Care Notebook

Gather information you already have.

Gather any health information about your child you already have. 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.

Look through the pages of 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. The Care Notebook pages are available from the Internet at www.fvnd.org. Go to Library Page and choose the "Care Notebook."

Choose your child's most important information.

- ❑ What information do you look up 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.

Put the Care Notebook together.

- ❑ Everyone has a different way of organizing information. The only important thing is to make it easy for you to find again. Here are some suggestions for supplies used to create a Care Notebook:
- ❑ 3-ring notebook or large accordion envelope. Hold papers securely.
- ❑ Tabbed dividers. Create your own information sections.
- ❑ Pocket dividers. Store reports.
- ❑ Plastic pages. Store business cards and photographs.

Apps and Technology

Cellphones and Tablets have changed the way we keep and view information. These days not many people leave the house without a cell phone, which makes them a great tool. Many families are using app technology instead of paper to keep track of their complex child's needs and information. Here are a few examples of health tracking apps. By searching your app store, you may find more as they are being developed all the time.

Apple/Android/Web Browser

CarePassport (Free) co-developed in collaboration with Massachusetts General Hospital. Patients can view their medical records and securely share with their healthcare providers. CarePassport allows patients to receive educational materials related to their care, authorize family members to access their information through secure proxy settings, and use navigation maps to drive to their appointments or arrange rides via Uber.

Apple Only Apps

Caremap (Free) developed by Boston Children's Hospital is a secure place to put the most critical information about your child's health, emergency care, allergies, and medical history. It is shareable with family members, teachers, and caretakers.

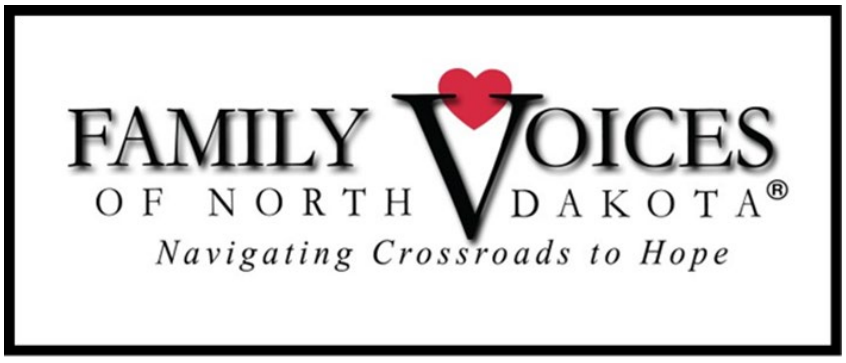
Child Health Tracker (Small Fee) the Child Health Tracker App by Healthy Children (a branch of the American Academy of Pediatrics) is handy because it stores your child's medical information, healthcare providers, and a medication tracker. It also has information from AAP about immunizations and more.

Epsy (Free) is a free seizure tracker for epilepsy. It helps you track and manage seizures, triggers, and medication for more clarity in everyday life. It is HIPPA compliant and a great tool to share important information with your child's neurologist.

FVND Care Notebook

Contents

Child and Family Information



Child's Page

My name is:

My nickname is:

My pet is a:

My pet's name is:

My friends' names are:

My FAVORITES

- Toys:
- Animals:
- Games:
- Hobbies:
- Songs:
- TV Shows:
- Other:

Favorite Foods:

Least favorite foods:

When I am happy I:

When I am sad I:

When I feel pain I:

Things I need help with (like washing, dressing, or brushing teeth):

Things I can do for myself (but thanks for asking!):

Notes:

If you need to know something else, ask me or ask _____, who can be reached at _____.

Child's Page con't

Use this page for your child's words and thoughts about their life now as well as later.

Date:

Family Information

Child's Name:		Nickname:
Date of Birth:	SSN:	Blood Type:
Diagnosis:		Phone:
Address:		
Legal Guardian:		

Mother's Name:		Nickname:
SSN:	Day Phone:	Evening Phone:
Address:		

Father's Name:		Nickname:
SSN:	Day Phone:	Evening Phone:
Address:		

Sibling's Name:	Age:
Sibling's Name:	Age:
Sibling's Name:	Age:
Sibling's Name:	Age:
Sibling's Name:	Age:

Other household members:

Important Family Information:

Languages Spoken at home:	
Other Language(s):	
Interpreter Needed? (yes/no)	
Preferred Interpreter? Name:	Phone:

EMERGENCY CONTACT	Name:
Day Phone:	Evening Phone:
Address:	

Emergency Preparedness

for Children with Special Health Care Needs

Children with special health care needs have very unique medical histories and require very special medical treatment. If an emergency physician does not have access to this important information, these children are in danger of delayed treatment, unnecessary tests, and even serious errors. It is extremely important, then, that parents and physicians work together to give emergency physicians access to the special information they need to properly care for children with very special health care needs.

To address this problem, the American Academy of Pediatrics and the American College of Emergency Physicians have developed the Emergency Information Form. This simple form is used to record health information for children with special health care needs and should be kept in multiple locations for easy access by physicians and emergency medical personnel.

To complete this important form, follow these easy instructions:

1. **GET THE FORM:** Get the Emergency Information Form from the child's primary care physician, specialist, or the local emergency room.
2. **FILL IT OUT:** Begin filling out the form to the best of your ability. Take the form to the child's primary care physician or specialist and ask them to finish filling out the form.
3. **KEEP IT:** Keep 1 copy of the form in each of the following places:
    a. **DOCTORS:** On file with each of the child's physicians, including specialists.
    b. **ER:** On file with the local emergency rooms where the child is most likely to be treated in the case of an emergency.
    c. **HOME:** At the child's home in a place where it can be easily found, such as the refrigerator.
    d. **VEHICLES:** In each parent's vehicle (i.e., glove compartment).
    e. **WORK:** At each parent's workplace.
    f. **PURSE/WALLET:** In each parent's purse or wallet.
    g. **SCHOOL:** On file with the child's school, such as in the school nurse's office.
    h. **CHILD'S BELONGINGS:** With the child's belongings when traveling.
    i. **EMERGENCY CONTACT PERSON:** At the home of the emergency contact person listed on the form.
4. **REGISTER:** Consider registering the child, if he or she is not already registered, with Medic Alert®. Send Medic Alert® a copy of the form so that they can keep it stored in their central database, which is easily accessible by emergency medical personnel.
5. **UPDATE:** It is extremely important that you update the form every 2-3 years, and after any of the following events:
    a. Important changes in the child's condition.
    b. The performance of any major procedure.
    c. Important changes in the treatment plan.
    d. Changes in physicians.

Now, if your child ever has an emergency, the emergency medical personnel will have easy access to your child's very unique medical history, allowing them to provide your child with the best medical care available. Thank you for your cooperation!

Very truly yours,

American Academy of Pediatrics
American College of Emergency Physicians
Emergency Medical Services for Children

American Academy of Pediatrics, 141 Northwest Point Blvd., Elk Grove Village, IL, 60007,
847-434-4000

Emergency Information Form for Children with Special Needs

Last name:

American College of Emergency Physicians®

American Academy of Pediatrics

Date form completed	Revised	Initials
By Whom	Revised	Initials

Name: **Birth date:** **Nickname:**

Home Address: **Home/Work Phone:**

Parent/Guardian: **Emergency Contact Names & Relationship:**

Signature/Consent*:

Primary Language: **Phone Number(s):**

Physicians:

Primary care physician: **Emergency Phone:**

Fax:

Current Specialty physician: **Emergency Phone:**

Specialty: **Fax:**

Current Specialty physician: **Emergency Phone:**

Specialty: **Fax:**

Anticipated Primary ED: **Pharmacy:**

Anticipated Tertiary Care Center:

Diagnoses/Past Procedures/Physical Exam:

1.

2.

3.

4.

Synopsis:

Baseline physical findings:

Baseline vital signs:

Baseline neurological status:

*Consent for release of this form to health care providers

Last name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

1.

2.

3.

4.

5.

6.

Significant baseline ancillary findings (lab, x-ray, ECG):

Prostheses/Appliances/Advanced Technology Devices:

Management Data:

Allergies: Medications/Foods to be avoided **and why:**

1.

2.

3.

Procedures to be avoided **and why:**

1.

2.

Immunizations (mm/yy)

Dates					
DPT					
OPV					
MMR					
HIB					

Dates					
Hep B					
Varicella					
TB status					
Other					

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings with Specific Suggested Managements

Problem	**Suggested Diagnostic Studies**	**Treatment Considerations**

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: **Print Name:**

Health Care Appointment Log

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Doctor's Name	Appointment Date and Time	Questions to Ask

Medications

Allergies:		
Pharmacy:		
Phone:	Fax:	Email:
Address:		

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

Growth Tracking Form

DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	CHECKED BY

Diet Tracking Form

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

Lab Work/Tests/Procedures

DATE	TEST	RESULT	COMMENT

Hospital Stay Tracking Form

DATE	HOSPITAL	REASON	NOTES

Medical and Surgical Highlights

DATE	PROCEDURE	RESULT	COMMENTS

Respiratory

Use this page to talk about your child's respiratory care needs. Describe the care or treatments your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

Date:

Nutrition

Use this page to talk about your child's nutritional needs. Describe foods and any nutritional formulas your child takes, any food allergies or restrictions, and any special feeding techniques, precautions, or equipment used for feedings. Describe any special mealtime routines your family and child have.

Date:

Dental

Child's Name:	
Dentist's Name:	
Dentist's Telephone:	
Dentist's Address:	

All children should have routine dental care. Such care may be even more important when your child has a special health care need. He or she may need to be followed by a dentist with special skills. Consult 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 can use the space below to keep track of your child's dental appointments.

Date	Time	Appointment Information

Care Schedule

TIME	CARE
Morning	
Afternoon	

TIME	CARE
Evening	
Night	

Equipment

Medical Equipment Supplier (DME Supplier):		
Contact Person:		
Phone:	Fax:	E-Mail:
Contact Person:		
Phone:	Fax:	E-Mail:
Address:		
Notes (delivery schedule, order schedule, etc.):		

Name of Equipment:	
Description (brand name, size, etc.):	
Date Obtained:	Service Schedule:
Contact Person:	Phone:

Name of Equipment:	
Description (brand name, size, etc.):	
Date Obtained:	Service Schedule:
Contact Person:	Phone:

Name of Equipment:	
Description (brand name, size, etc.):	
Date Obtained:	Service Schedule:
Contact Person:	Phone:

Name of Equipment:	
Description (brand name, size, etc.):	
Date Obtained:	Service Schedule:
Contact Person:	Phone:

Name of Equipment:	
Description (brand name, size, etc.):	
Date Obtained:	Service Schedule:
Contact Person:	Phone:

Supplies

Medical Equipment Supplier (DME Supplier):		
Contact Person:		
Phone:	Fax:	E-Mail:
Contact Person:		
Phone:	Fax:	E-Mail:
Address:		
Notes (delivery schedule, order schedule, etc.):		

ITEM	DESCRIPTION	QUANTITY	NOTES

Therapists

Occupational Therapist (OT):		
Start Date:		
Agency/Hospital/Clinic:		
Address:		
Phone:	Fax:	E-Mail:
Notes:		

Physical Therapist (PT):		
Start Date:		
Agency/Hospital/Clinic:		
Address:		
Phone:	Fax:	E-Mail:
Notes:		

Speech-Language Pathologist:		
Start Date:		
Agency/Hospital/Clinic:		
Address:		
Phone:	Fax:	E-Mail:
Notes:		

Therapy

Use this page to track your child's therapy goals. This will allow you to measure improvement or know when to change the goals. Only use this log if it applies to your child.

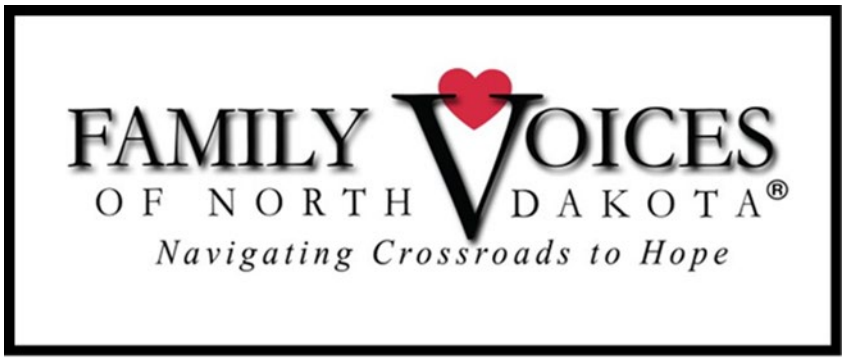
Physical ☐ Occupational ☐ Speech ☐ Behavioral ☐

Child's Name: _____

Month/Year: _____

			Weekly: Achieved (A)/ Continue (C)				
Number	Goal	Comments	1	2	3	4	5

Social/Emotional



Activities of Daily Living

Use this page to talk about your child's abilities to feed him or herself, bathe, get dressed, use the bathroom, comb hair, brush teeth, etc. Describe what your child can do by him or herself and any help or equipment your child uses for these activities. Describe any special routines your child has for bath time, getting dressed, etc.

Date:

Communication

Use this page to talk about your child's ability to communicate and to understand others. Describe how your child communicates. Include sign language words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

Date:

Coping/Stress Tolerance

Use this page to talk about how your child copes with stress. Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. Describe what things upset your child and what your child does when upset or when he or she has "had enough." Describe your child's way of asking for help and things to do or say to comfort your child.

Date:

Mobility

Use this page to talk about your child's ability to get around. Describe how your child gets around. Include what your child can do by him or herself and any help or equipment your child uses to get around. Describe any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc.

Date:

Rest/Sleep

Use this page to talk about your child's ability to get to sleep and to sleep through the night. Describe your child's bedtime routine and any security or comfort objects your child uses.

Date:

Social/Play

Use this page to talk about your child's ability to get along with others. 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.

Date:

Recreation

A number of organizations have programs designed to give children and adults with special needs Recreation opportunities. These include local park and recreation programs. Check with your providers to find out more about recreation opportunities close to your home. Some parents include brochures and activity calendars in this section of their Family Voices of North Dakota Care Notebook.

Recreation Opportunity:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Schedule:	Website:	
Notes:		

Recreation Opportunity:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Schedule:	Website:	
Notes:		

Recreation Opportunity:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Schedule:	Website:	
Notes:		

Education

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Early Intervention

Early intervention means early assistance. In North Dakota, a special kind of partnership between parents and professionals gives every child the best possible start in life. The Department of Human Services' Infant Development/Early Intervention programs are designed to help your child and your family get the supports you need. The Early Intervention Program is designed to identify children at risk for developmental delays at an early age, when the right help can make all the difference. This program is designed to support eligible children and families in enhancing a child's potential growth and development from ***birth to age three.***

My Early Intervention Program Agency:

Date Contacted:	Date started in program:
Service Coordinator:	
Service Providers (therapist, nurse, etc.):	

Address:		
Phone:	Fax:	Email:
Schedule:	Website:	
Notes:		

Region	Human Service Center	Toll Free Number	Phone Number
Williston	Northwest	800-231-7724	701-774-4600
Minot	North Central	888-470-6968	701-857-8500
Devils Lake	Lake Region		701-665-2200
Grand Forks	Northeast		701-795-3000
Fargo	Southeast	888-342-4900	701-298-4500
Jamestown	South Central	800-639-6292	701-253-6300
Bismarck	West Central	888-328-2662	701-328-8888
Dickinson	Badlands	888-227-7525	701-227-7500

Transitions-Looking ahead

All families experience many transitions as their children age. Three predictable transitions 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, working 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 get done today. You may find it helpful, though, to write down a few ideas about your child's and family's future. You might start by thinking about the strengths that your child and family have. How can these strengths help you plan for "what's next" and to reach your long-term goals? What are your dreams and your fears about the future of your child and family?

Date:

Contacts

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Home Care Providers

Home Care Agency:		
Start Date:		
Case Manager:		
Other Contacts (scheduler, billing, etc.):		
Primary Care Nurse:		
Phone:	Fax:	Email:
Notes:		

Home Care Agency:		
Start Date:		
Case Manager:		
Other Contacts (scheduler, billing, etc.):		
Primary Care Nurse:		
Phone:	Fax:	Email:
Notes:		

Home Care Agency:		
Start Date:		
Case Manager:		
Other Contacts (scheduler, billing, etc.):		
Primary Care Nurse:		
Phone:	Fax:	Email:
Notes:		

School Contacts

School District:

Address:		
Phone:	Fax:	Website:

Special Education Coordinator:

Address:		
Phone:	Fax:	Email:

502 Accommodation Plan Coordinator:

Address:		
Phone:	Fax:	Email:

District Nurse assigned to child's school:

Address:		
Phone:	Fax:	Email:

School/Preschool:

Address:		
Phone:	Fax:	Email:

Principal/Administrator:

Address:		
Phone:	Fax:	Email:

Classroom Teacher:

Address:		
Phone:	Fax:	Email:

Resource Instructor:

Address:		
Phone:	Fax:	Email:

Aide/Assistant/Intervener:

Address:		
Phone:	Fax:	Email:

Special Education Director/Teacher:

Address:		
Phone:	Fax:	Email:

Therapist:

Address:		
Phone:	Fax:	Email:

Respite Care

Respite Care Provider:		Start Date:
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	Email:
Schedule:	Website:	
Notes:		

Respite Care Provider:		Start Date:
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	Email:
Schedule:	Website:	
Notes:		

Respite Care Provider:		Start Date:
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	Email:
Schedule:	Website:	
Notes:		

If Applicable*		
Fiscal Agent:		
Contact Person:		
Phone:	Fax:	Email:

Pharmacy

Medical professionals suggest that, if possible, you use one pharmacy for all your prescription medicine needs. In this way, your pharmacist may keep track of all medications being used and any possible problems with interactions between medications. Sometimes; however, you may need to have prescriptions filled at your neighborhood pharmacy and other times you may need to have them filled at the hospital pharmacy. Use this space to keep track of all your pharmacy providers.

Pharmacy:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Pharmacy:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Pharmacy:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Important information for the pharmacist (Such as allergies to medication):

Transportation

Transportation (To/From appointments):		
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	Email:
Important Info (such as bus route, rules regarding pick-up, etc.):		

Transportation (To/From appointments):		
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	Email:
Important Info (such as bus route, rules regarding pick-up, etc.):		

Family Resources

Support Group/Organization:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Religious Organization:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Counseling Services:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Department of Health and Human Services:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Other:		
Contact Person:		
Address:		
Phone:	Fax:	Email:
Notes:		

Insurance

Primary Insurance Company:		Policy#
Contact Person / Title:		
Address:		
Phone:	Fax:	Email:
Notes:		

Secondary Insurance Company:		Policy#
Contact Person / Title:		
Address:		
Phone:	Fax:	Email:
Notes:		

Medicaid: (HMO Name if applicable – this is the company name that appears above your child's name and ID# on the Medicaid ID Card)		ID#
Eligibility Worker:		
Office/Location of Eligibility Worker:		
Phone:	Fax:	Email:
Notes:		

Supplemental Security Income (SSI):		
Contact Person / Title:		
Address:		
Phone:	Fax:	Email:
Notes:		

Other:		Policy#
Contact Person / Title:		
Address:		
Phone:	Fax:	Email:
Notes:		

Notes

Acknowledgments

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