



MARYLAND Department of Health

Larry Hogan, Governor · Boyd Rutherford, Lt. Governor · Dennis Schrader, Secretary

Dear Parents and Caregivers,

This care notebook has been designed for you, the parents and caregivers of a child with special health care needs. You play an important role in your child's care and doctors and nurses rely on you to give them information about your child's health. It is helpful to have all your child's health care information organized and in one place so you can manage it easily. Please use this health care notebook to adapt it to fit your child's needs (see *Creating Your Care Notebook* on the next page).

The Office for Genetics and People with Special Health Care Needs is also a resource for locating information on services you may need for your child. Please call our Special Health Care Needs Resource Line on 410-767-1063 or 1-800-638-8864 for help. You can also log on to our Resource Locator website: <http://specialneeds.dhmh.maryland.gov/> to locate resources for children and youth with special needs.

If you have any questions, please contact our parent resource coordinator, Ms. Angela Sitter at the above number. She will be happy to assist you.

Regards,

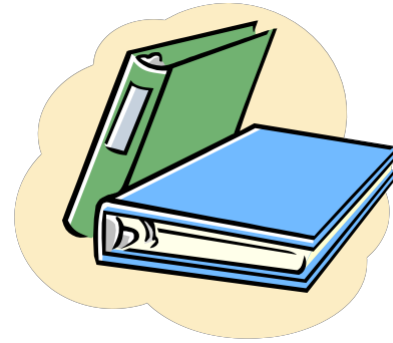
Jed Miller, MD
Acting Director
Office for Genetics and People with Special Health Care Needs

Disclaimer

This Patient Care Notebook is intended to assist you in maintaining and organizing your child's medical record information. You should take the Notebook to your child's medical appointments and emergency visits to assist you in providing the necessary medical information to your child's medical provider and to update information from the current doctor visit. Please keep the Patient Care Notebook in a safe location. The State of Maryland will not be responsible for loss or misplaced Patient Care Notebook.

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://phpa.health.maryland.gov/genetics/Pages/create_care_notebook.aspx
- ◇ 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.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.

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: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

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Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
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>
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____
* _____	_____	_____

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, c. 2007

Care Summary: Communication



Use this page to write 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: _____

Care Summary: Rest/Sleep



Use this page to write 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: _____

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 _____

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Clinic/Hospital Name _____

Frequency of Visits (how often) _____

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Frequency of Visits (how often) _____

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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

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: _____

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

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

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❖ 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: _____

Appointment Log



DATE	PROVIDER	QUESTIONS/PROBLEMS TO BE DISCUSSED	REASON SEEN/CARE PROVIDED	NEXT APPOINTMENT

Growth Tracking Form



DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	CHECKED BY

Hospital Stay Tracking Form



DATE	HOSPITAL	REASON	NOTES

My Child's Profile

Child's Name: _____ DOB: _____

Respiratory Care:



Not Applicable to my child

- Oxygen:**

Liters	Route	Start Date
_____	_____	_____

- SVN:**

Medication	Amount	Frequency
_____	_____	_____

- Suctioning:**

Route	Catheter size	Frequency
_____	_____	_____

- Tracheostomy:**

Size/Brand	Change Frequency
_____	_____

- Ventilator:**

Type	Settings: IMV	SIMV	Volume
_____	_____	_____	_____
	Peak Pressure	PEEP	Rate
	_____	_____	_____

- Pulse Ox:**

Type	Settings: Low Alarm	High Alarm
_____	_____	_____

- Apnea Monitor:**

Type	Settings: High Heart Rate	Low Heart Rate
_____	_____	_____
	Apnea settings in seconds	

- CPAP:**

Type	Settings: Pressure
_____	_____

Comments:



PROFILE / II. EQUIPMENT / SUPPLIES / SERVICES

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:			

Medications

Allergies:

Pharmacy:

Phone:

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

Child's Name _____ Date of Birth _____

Phone Log

○ It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)



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)			

Lab Work/ Tests/ Procedures

.....

DATE	TEST	RESULT	COMMENTS

Child's Name: _____

Date of Birth: _____

MONTHLY CONSUMABLE SUPPLY LOG



Child's Name:	Phone:	
Address:	Physician:	
Insurance Company Responsible for Supplies:		
Policy #:	Authorization #:	
Insurance Phone:	Insurance Contact:	
Supplier:	Phone:	Contact:

Monthly consumable supplies are disposable supplies you need to re-order monthly. For example: catheters, feedings bags, formula, saline, gauze, syringes, etc. **Use a separate sheet for each supplier.**

Date	Description	Amount	Manufacturer	Order Number



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) _____

Out-of-Pocket Expense Log

Use this log to track expenses incurred that are not covered by insurance. Make sure to save all receipts for tax purposes.



Date	Item Description / #	Cost	Date	Item Description / #	Cost

Out-of-Pocket Expense Log

EXPENSE LOG

Date	Item Description / #	Cost	Date	Item Description / #	Cost

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: _____

☼ 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: _____

Health Care As You Move to Adult Life
Maryland Office for Genetics and People with Special Health Care Needs
For more information visit:

<http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

Health care is important to be successful in the transition to work, independent living and adult life. As an adult, your child may take on more responsibility for their healthcare. Some pediatricians will see young adults until they are 21 years old. Unless your child sees a doctor that cares for both children and adults, he or she will need to transition to an adult doctor at some point. This is important because good health habits and health problems change as we get older. Here are some things you and/or your child will need to do:

- Learn about your health issues and how to explain your healthcare needs. Make a list of all the things you will need to keep yourself healthy.
- See your doctor on a regular basis (at least once a year) to help you stay healthy and see a dentist every 6 months. You can start at your next visit, even while you are still seeing a pediatric doctor.
 - Write down questions before your visit.
 - Spend time alone with your doctor or the nurse to discuss your health concerns.
- Check to see if your immunizations (shots) are up to date.
- Make sure that you know how to tell when you need medical attention quickly. Know when and where to call.
- Keep a record of your appointments, medical history, medications and phone numbers of doctors.
- Begin to make your own medical appointments and fill your own prescriptions.
- Learn about your health insurance and what it pays for. Know what you need to do to keep your insurance active.
- Talk to your doctor about when is a good time for you to transfer your care to a doctor who cares for adults and develop a plan.
- Keep a notebook that helps prepare you to transfer to your new doctor. The notebook should contain important information about your medical history, medications, specialists, and insurance.
- Be involved in decisions affecting your health care, like choosing a doctor and making decisions about health insurance.
- **REMEMBER, BEING INDEPENDENT DOES NOT MEAN YOU HAVE TO DO THINGS ALONE.** It means you take responsibility, and that you ask for help and support when you need it.
- Ask questions! Be part of the plan!

Getting Started:

- _____ I know the names of my medical conditions and how they affect me.
- _____ I know the names of my medications, what they are for, and when to take them.
- _____ I know the name of my doctor(s) and how to make an appointment if I need one.
- _____ I know how to get my prescriptions filled.
- _____ I know what my insurance options are once I turn 18. Maryland Transitioning Youth (<http://www.mdtransition.org/Health%20Care.htm> or 1-800-637-4113) can help you get started, or check with your service or transition coordinator.
- _____ I have adult health care providers who accept my insurance. Ask for a list of providers from your insurance company, or if you have already chosen a doctor, ask if they take your insurance.
- _____ I have checked if my adult insurance will cover all of my health care needs (such as medicines, therapies and medical equipment). If not, I have looked into other options for assistance. Maryland Transitioning Youth (<http://www.mdtransition.org/Health%20Care.htm> or 1-800-637-4113) can help you get started, or check with your service or transition coordinator.

RESOURCES

1. The Center for Children with Special Needs – Teen Transition Notebook (Also, for use with Young Adults) <http://cshcn.org/teen-transition-adult-health-care>
2. Got Transition? National Health Care Transition Center’s website. <http://www.gottransition.org/youth-information>
3. Healthy Transitions
New York State’s website for moving from pediatric to adult health care http://healthytransitionsny.org/skills_media/tool_show
4. KidsHealth - Educates youth on health basis, diseases and conditions - http://kidshealth.org/teen/index.jsp?tracking=T_Home
5. The Youthhood: life planning for your future - <http://www.youthhood.org>
6. Maryland Children and Youth with Special Health care Needs Resource Locator - Online database designed to help families of children with special health care needs, youth and providers find needed resources. <http://specialneeds.dhmf.maryland.gov>

iTransition-Health: Resources for Youth and Young Adults

Check Your Skills

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration, Office for Genetics and People with Special Health Care Needs.

For more information visit: <http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

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).

Source: *Envisioning My Future: A Young Person's Guide to Health Care Transition* from Children's Medical Services, Florida Department of Health. Available at: http://hctransitions.ichp.ufl.edu/pdfs/envisioning_my_future.pdf

**iTransition-Health: Resources for Youth and Young Adults
Parent's Health Care Check List for Transitioning Youth**

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration,
Office for Genetics and People with Special Health Care Needs.

For more information visit: <http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

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>

**iTransition-Health: Resources for Youth and Young Adults
Parent's Health Care Check List for Transitioning Youth**

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration,
Office for Genetics and People with Special Health Care Needs.

For more information visit: <http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

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>

Care Summary:
Transitions-Looking Ahead

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Your child and family may go through or have many transitions, small and large, over the years. Three key transitions are: when your child reaches school age, when he or she nears adolescence, and when your child moves from adolescence into adulthood. 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 of others.

It's not always easy to think about the future. There may be many things, including what has to be done today, that keep you from looking ahead. It may be helpful to take some time to jot down a few ideas about your child's and family's future. What are your child's and family's strengths? How can these strengths help you plan for "what's next" and for reaching long term goals? What are your dreams and your fears about your child's and family's future?

Date: _____

Care Summary: Child's Page-Now and Later

.....
Use this page for your child's words and thoughts about his or her life now as well as later. What are your child's dreams? What does he or she do well now that might give direction for life later? What does your child want to be when he or she grows up?

Date: _____

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_____

Living Arrangements

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

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

Home Manager

Name and Phone Number _____

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 _____

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.

TRUSTS

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

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

Attorney/Agency/Company managing the trust

Address

Phone Number

Location of a copy of the Trust_____

List agencies notified about the Trust_____

LAST WILL AND TESTAMENT

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

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

Attorney _____

Location of a copy of the Will _____

¹Durable Power of Attorney _____

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_____