Estimados Padres y Proveedores de cuidados:

Este Cuaderno de Cuidado del paciente ha sido diseñado para ustedes, los padres y/o personas responsables de un menor con necesidades especiales de salud. Usted juega un papel importante en el cuidado de su hijo(a); y los médicos y enfermeras dependen de la información que usted proporcione acerca de la salud de su hijo(a). Sería conveniente tener la información del cuidado de salud de su hijo(a) organizada y en un sólo lugar a fin de administrarla fácilmente. Por favor, use el Cuaderno de Cuidado para adaptarlo a las necesidades de su hijo(a) (Diríjase a la sección de – Creando Su Cuaderno de Cuidado para ayuda).

La Oficina de Genética y para las Personas con Necesidades Especiales de Cuidado de Salud sirve como recurso para encontrar información acerca de los servicios que podrían necesitar para su hijo(a). Por favor, visite nuestro sitio Web para la Localización de Recursos: http://specialneeds.dhmh.maryland.gov/ o llame a nuestra Línea de Recursos para obtener ayuda en encontrar lo que necesita al 410-767-1063 o al 1-800-638-8864.

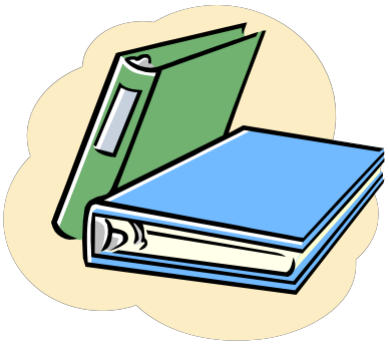
Si tiene alguna pregunta o comentario, no dude en comunicarse con nosotros en los números que hemos listado. ¡Gracias por su interés en el Cuaderno de Atención Médica!

Sinceramente,

Oficina de Genética y para las Personas con Necesidades Especiales de Cuidado de Salud

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.dhmh.maryland.gov/genetics/SitePages/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:

* _____
* _____
* _____
* _____
* _____
* _____
* _____
* _____
* _____
* _____
* _____
* _____

Medical Professionals:

PCP: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Doctor: _____
Specialty: _____
Phone: _____

Name:_____ **Birth Date:**_____

***ALLERGIES*:**_____

Medications:

Name:	Dose:	Frequency:
*		
*		
*		
*		
*		
*		
*		
*		
*		
*		
*		

Nutritional Supplements:

Name:	Dose:	Frequency:
*		
*		
*		

Daily Procedures:

*
*
*

Surgeries/ Hospitalizations(recent):

Date:	Hospital:	Reason:
*		
*		
*		
*		
*		
*		
*		
*		
*		
*		
*		
*		

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.

Clear Page

Maryland Care Notebook. Adapted from the Massachusetts Department of Health, 2004 (www.mass.gov/dph/fch/directions)

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 _____

_____

_____

Maryland Care Notebook. Adapted from the Massachusetts Department of Health, 2004 (www.mass.gov/dph/fch/directions)

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: _____

Care Summary:
Activities of Daily Living

Use this page to write 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 bathtime, getting dressed, etc.

Date: _____

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:
Coping/Stress Tolerance

Use this page to write 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: _____

Care Summary:
Social/Play

Use this page to write 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: _____

Care Summary:
Mobility

Use this page to write 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: _____

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) _____

Start Over

Maryland Care Notebook. Adapted from the Massachusetts Department of Health, 2004 (www.mass.gov/dph/fch/directions)

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) ____________

Start Over

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

- 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

(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

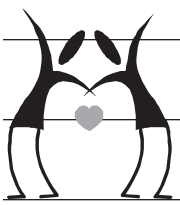
My Child's Profile

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:



Clear Form

Maryland Care Notebook. Adapted from the Alameda Medical Home Project for Children with Special Health Care Needs, California

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:	☐	☐	

Start Over

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: _____

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)			

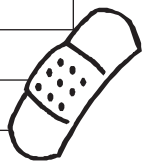
My Child's Profile

Child's Name: _____ DOB: _____

Allergy Record Log:

Allergic reactions can be life threatening. Keep good records on all reactions.

Date	Allergy	Type of Reaction



Start Over

Maryland Care Notebook. Adapted from the Alameda Medical Home Project for Children with Special Health Care Needs, California

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)____________________

Maryland Care Notebook. Adapted from the Massachusetts Department of Health, 2004 (www.mass.gov/dph/fch/directions)

Clear Page

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

Maryland Care Notebook. Adapted from the Alameda Medical Home Project for Children with Special Health Care Needs, California

Out-of-Pocket Expense Log

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

Start Over

Maryland Care Notebook. Adapted from the Alameda Medical Home Project for Children with Special Health Care Needs, California

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 Accomodation 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:_____
_____

Start Over

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.dhmh.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 Escellence 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 Escellence in Developmental Disabilities. Available at: http://www.waisman.wisc.edu/wrc/pdf/pubs/TAHC.pdf

Care Summary:
Transitions-Looking Ahead

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_____

Clear Page

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.

_____

_____

_____

Clear Page

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_____

_____

Clear Page

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 _____

[1]Durable Power of Attorney _____

Clear Form

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_____

Clear Page