

PLANNING FOR ADULT HEALTH CARE

A Guide for Parents and Caregivers Transitioning Youth with
and without Disabilities from Pediatric to Adult Care

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INTRODUCTION

Teaching your youth to be responsible for their health care is a journey that begins in childhood. As they develop and grow into the role of an adult, on-going encouragement and assistance is needed from their parents, caregivers and network of family and friends as they take charge of their health. This guide is about the steps and approaches you can take to prepare your youth with managing their health needs and transitioning to an adult health care provider.

For some parents, whose children have required a lot of assistance and support to meet the challenges of their disability, this vision of independence is not easily attained. This guide offers you many ideas about how to make this a smooth and successful process regardless of your youth's disability and/or medical condition.

You may always need to be available to answer questions and assist your young adult according to their abilities. But it is critical that your young adult develop the skills, confidence and strategies to navigate the adult health care system in advance of turning 18. And after that, there is no magic date when your young adult won't need to ask you questions.

WHAT IS HEALTH CARE TRANSITION?

Health care transition is one aspect of the many transitions that occur in the movement from adolescence to adulthood. Preparing for health care transition often receives less attention than preparing for other transitions in school, work, relationships, and independent living. Health care transition, according to the Society for Adolescent Medicine, is the **purposeful, planned movement of adolescents from pediatric to adult health care**. It is a "process" where the responsibility for managing health care shifts from the parent to the young adult. It is an active, multifaceted process that involves the medical, psychosocial, educational and vocational needs of youth.

WHY IS HEALTH CARE TRANSITION SO IMPORTANT?

Having the ability to anticipate and prepare for future health care concerns improves the health and wellness of youth and young adults with special health care needs and/or disabilities. Establishing a well thought out plan or process on how your youth will manage and respond quickly to health concerns that may greatly impact their overall wellness and ability to maintain a healthy lifestyle offers comfort and reassurance for them and everyone involved in their life.

WHAT DOES THE HEALTH CARE TRANSITION TIMELINE LOOK LIKE FOR YOUTH AND FAMILIES?

Parents of children and youth with special health care needs and disabilities need to plan, connect, advocate and find information on behalf of their child. Planning ahead is very important and makes a difference. The American Academy of Pediatrics suggests starting health care transition at the age of 12.

It is up to you to ensure your child knows and understands his or her medical condition. Talk about it; let them meet other children and youth with similar needs. Give them words to explain their disability to other children they meet. It is important to give your child's disability the proper name, and explain what that means. This can prevent anxieties and better prepare your child to seek appropriate health and support services later in life.

Age 14-16

According to developmental ability youth can begin to:

- ✓ Develop knowledge of their special health care needs
- ✓ Take responsibility in making appointments and getting prescriptions refilled
- ✓ Explore appropriate work and volunteer opportunities
- ✓ Talk to medical providers about age appropriate information such as, physical, emotional, and sexual development

According to your child's needs, parents can begin to:

- ✓ Make arrangements for the steps above if child is unable to be independent
- ✓ Keep a health record for youth. Include all medical paperwork
- ✓ Explore options of transition planning through the local school district
- ✓ Explore the eventual need to transfer your child's care to adult providers

Age 16-18

According to developmental ability youth can begin to:

- ✓ Take responsibility in making appointments and getting prescriptions refilled
- ✓ Contact Georgia Vocational Rehabilitation Agency to explore vocational assistance if needed
- ✓ Attend all meetings where future plans are discussed (school IEPs or doctor's office)
- ✓ Research adult health care providers for transfer of medical care
- ✓ Explore employment opportunities
- ✓ Explore living arrangements

According to your child's needs, parents can begin to:

- ✓ Make arrangements for the steps above if child is unable to be independent
- ✓ Explore options for health care coverage
- ✓ Check eligibility for SSI from the Social Security Administration
- ✓ Research adult health care providers for transfer of medical care
- ✓ Explore the option of legal guardianship or the many alternatives to guardianship if child's special needs interfere with the ability to make financial and medical decisions

Age 18-20

According to developmental ability young adult can begin to:

- ✓ Finalize health care coverage as an adult
- ✓ Transfer medical care from pediatric providers to adult providers
- ✓ Check eligibility for SSI from the Social Security Administration
- ✓ Contact Georgia Vocational Rehabilitation Agency to explore vocational assistance if needed
- ✓ Contact the disability student services office if attending college and accommodations are needed
- ✓ Explore employment opportunities

According to your child's needs, parents can begin to:

- ✓ Make arrangements for the steps above, if young adult is unable to be independent
- ✓ Complete and submit a release of information signed by young adult if parent/caregiver would like to participate in their care
- ✓ Provide documentation of legal guardianship to all providers if needed

Age 20-21

According to developmental ability young adult can begin to:

- ✓ Explore living arrangements. If assistance is needed contact the nearest Center for Independent Living
- ✓ Learn about and continue to investigate adult services there may be need for
- ✓ Transfer all medical care from pediatric providers to adult providers
- ✓ Explore employment opportunities

According to your child's needs, parents can begin to:

- ✓ Make arrangements for the steps above, if young adult is unable to be independent
- ✓ Complete and submit a release of information signed by young adult if parent/caregiver would like to participate in their care
- ✓ Explore private duty nursing options if young adult is receiving in-home nursing.

ASSESSING YOUR SITUATION

Before you can decide where to go, you need to know where you are. What do you have now, what do you need, who can get it for you? Take a few minutes to complete the appropriate assessment(s) beginning on page 11. Having a clear and thought-out plan will make the transitional journey more enjoyable and less stressful. The parent, youth (depending on the age and understanding) and providers should discuss and identify the various needs of the youth in transition. The Health Care Transition Action Plan on page 16 may be used to identify concerns, actions required. Below are a few starter questions.

- ✓ What are the current medical needs of your youth?
- ✓ What are the expected future medical needs of your youth?
- ✓ When should your youth receive regular physicals and routine screenings such as cholesterol, hearing, vision, blood pressure monitoring etc.?
- ✓ Who can help assist you in learning about specific health care for your youth's medical condition?
- ✓ At what age will the current provider no longer treat your child?

- ✓ Is there an adult provider that your current provider can refer your youth to?
- ✓ Does your youth qualify for Medicaid or Medicare coverage?
- ✓ Will the pediatric provider help me put together a portable medical summary? And will they communicate with the new adult doctor during this transition time?
- ✓ If your teen is currently on a Government-Funded Program: How long are they eligible for this program? (Don't assume anything, often times there are different guidelines for people over 18.) What will they do when they are no longer eligible for this program?
- ✓ Explore all benefits and services that are provided to your youth which will/can be provided to adults with special needs. What paperwork needs to be in place?
- ✓ Is your youth receiving SSI? Should he/she apply? Where can the forms be found?

TEN STEPS TO HEALTH CARE TRANSITION

Steps for you and your family to take to help your child with special health care needs plan the move from pediatric to adult care.

- 1. Start Early!** There are some things you can do to get ready for transition even when your child is very young, like starting to keep a medical summary and teaching your child about his or her health care needs. It is important to plan for the future so you have everything ready when it is time for your child to make the move to the adult care.
- 2. Create a medical summary.** Put all of the important information about your child's health care in one place, including plans for an emergency. Ask your child's doctors for help and keep the information up-to-date. Give any new health care providers a copy of the summary so they will know all of the important details about your child's medical history. A sample medical summary is included on page 17.
- 3. Create a health care transition plan.** Work on a written health care transition plan with your child's primary care doctor. Include your child's future goals, what services he or she will need, who will provide them, and how they will be paid for. Start this plan by the time your child is 14 years old. Review and update the plan at least once a year. A sample transition plan is included on page 16.
- 4. Focus on responsibility for health care.** Help your child understand and take responsibility for his or her health care based on age and abilities. Find out what your child knows about his or her health care needs and fill in the gaps. Teach your child the skills that are needed to manage his or her health care. Encourage your child to participate in decisions about health. Your child's doctors can help you with this.
- 5. Consider the need for additional supports.** Some young people will be unable to make informed decisions about their health care in adulthood due to illness, mental illness, or a developmental disability. You should consider whether your child might need other types of support with health care as an adult, like a home health aid or personal care attendant.

6. Maintain wellness. Encourage a healthy lifestyle. Help your child start good habits that will continue into adulthood. This means emphasizing good nutrition and exercise, and teaching your child to make healthy choices. Talk with your adolescent about risky behaviors such as alcohol use and smoking. Discuss sexuality and relationships. These topics in some form are important for all adolescents. Ask your child's primary care doctor to address these issues as well.

7. Know your child's health insurance options. It is important to find out what types of private or public insurance your child will be eligible for as an adult. The possible options will depend upon things like your child's age, health conditions, income, and ability to work. It is also important to make sure that any new health insurance plan will meet the young person's needs. Look closely at the health plan costs and the benefits package. If you have already chosen health care providers who work with adults, check to see if these providers are in the plan.

8. Find new providers. Pick a primary care doctor (and specialist if needed) who works with adults. You can ask your young adult's current providers for a referral. Ask local support groups or other families that you know to recommend a doctor. You can also get a list of physicians from your young adult's insurance company. You and your young adult should interview possible doctors, and pick one that you think will meet their needs. Ask your young adult's current providers to speak with the doctor you have selected.

LET YOUR YOUNG ADULT TAKE CHARGE

One of the main differences between pediatric services and adult services is that pediatric services are family-driven while adult services are consumer-driven. And as a parent or caregiver you might find yourself between these two medical worlds that often do not communicate.

To begin the transition process you can discuss your plan to help your young adult take charge of their health care, and ask the doctor and office staff to assist you. This can begin with letting your young adult register at the desk when he or she arrives, presenting the insurance cards, going into the exam room alone, scheduling appointments with the staff and making the co-pays. It includes encouraging your young adult to ask their own questions, and encouraging staff to talk directly with your young adult.

While to a great extent your child's ability to become medically independent might depend on their cognitive and physical abilities, encouraging maximum independence should be the goal.

By the time your young adult is 16 or 17, help them call the doctor to make their own appointments. If your young adult has difficulty speaking on the phone, help them find an alternate way to schedule appointments. It is important that they know the date, time and location of all medical appointments, and the reason for each appointment. You can use a calendar with them to write down appointments. You can also mark on a calendar when they need to order or refill medications and other information.

Encourage your young adult to keep their doctor's phone number, insurance and pharmacy information with them at all times. This is information they will need to know as an adult. They need to be aware of how bills are paid, what they have as co-pay, and how all payments are made. Help them understand the type of coverage they have, and the limits to their coverage.

Encourage your young adult to be prepared for emergencies! Assist them in completing an emergency information form, with your names, and the names of others to contact in case of emergency. Don't forget to teach them ICE (In Case of Emergency). ICE is the contact that all emergency responders will look for in a cell phone. If your young adult carries a cell phone, help them program in the emergency contact number under ICE.

FINDING AN ADULT PROVIDER TO TREAT YOUR YOUNG ADULT WITH A DISABILITY

As your young adult approaches age 18, ask their doctor for input on the age to transfer care to an adult health care provider. Without planning for transition, teens and families may be surprised when they are refused care at a doctor's office or a children's hospital because they have "aged out." You don't want to find this out when your young adult is sick and needs help really fast. Plan ahead! Start planning at age 16 for your youth's transfer to doctors or nurse practitioners who care for adults. Actual transition is usually between ages 18 and 21.

You may need help in finding another doctor who understands the unique health needs of your young adult. Talk with your young adult's doctor and care coordinator about choices. Some families choose to have their young adult receive medical care from the physicians who treat the parents. This may work well for some families. Some families ask for referrals from their pediatrician. Others dialogue with other adults with disabilities to learn where they receive their care.

Some young adults can have all of their adult health needs met by a family doctor or nurse practitioner. Others will need referrals to specialists, such as orthopedists, urologists, cardiologists, or rehabilitation physicians. Your adult primary care provider will help you get referrals with these specialists.

There are many things for you and your young adult to consider—accessibility of the office, knowledge of the disability, other young adults with disabilities treated by this physician, and whether or not they will accept your young adult's insurance. In most cases, there will need to be an initial discussion of special health care needs in addition to the transfer of records that will routinely occur.

HERE ARE SOME TIPS FOR FINDING ADULT HEALTH CARE PROFESSIONALS

- Ask your young adult's current doctors, nurse practitioners or care coordinators who they recommend.
- Ask adults who have health needs like your young adult who they see.
- Look at your health insurance company booklet or website for approved providers.
- Call and interview doctors or nurse practitioners. Find out if they have experience with your young adult's health condition, how long it takes to get an appointment, and how quickly they can be seen if they get sick.

- Use the internet. Look at websites of the American Academy of Family Physicians, American College of Physicians-Internal Medicine, American Academy of Physical Medicine and Rehabilitation, American Academy of Orthopedic Surgeons or other specialists needed for your young adult's care.

PAYING FOR HEALTH CARE

Having health insurance is important for young people with chronic health conditions or disabilities. Insurance affects the ability to get medical care, stay well and prevent further health problems.

HEALTH COVERAGE CAN BE OBTAINED THROUGH ANY OF THE FOLLOWING:

- Employer-based coverage
- A plan purchased directly from an insurance company but not through work (these are usually expensive).
- A government-sponsored health plan: Medicaid, Medicare, TRICARE (military), or Georgia PeachCare for Kids (Children's Health Insurance Program (CHIP) to age 19).
- A government-sponsored program: Children's Medical Services (state children with special health care needs program -Title V CSHCN to age 21).

Medicaid is a government program which pays for medical services for individuals with disabilities with low incomes. Each state determines who is eligible, the scope of services, and payment for services. Some doctors do not take Medicaid. To learn more about Georgia Medicaid, visit www.dch.georgia.gov/medicaid. To learn more about Georgia Medicaid eligibility, contact your county Department of Family and Children Services.

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) service is Medicaid's child health program for individuals under the **age of 21**. It includes periodic screening, vision, dental, and hearing services and any medically necessary health care service. In some states EPSDT can cover in-home personal services or nursing care. It is important for teens and young adults to plan ahead for the transition from pediatric to adult Medicaid benefits because pediatric benefits are more generous. Consider the timing for getting diagnostic services and care, equipment such as a wheelchair, prosthetics or orthotics, glasses or hearing aids or other needed equipment.

Medicaid and SSI: **At age 18**, adult standards for disabilities are used. Many youth will no longer be eligible for SSI and may also lose Medicaid. Talk with someone at Social Security six months before your youth's 18th birthday so they can plan ahead.

- Some youth with disabilities did not receive SSI or Medicaid because their parents made too much money. At age 18 they may qualify for Medicaid because their parents' income is no longer counted.
- People on SSI can work and keep Medicaid. Talk with a Benefits Counselor at the Social Security Administration or at a Center for Independent Living for more information.

Special Medicaid Waivers. Each state has special Medicaid Waivers which provide Medicaid coverage for disabled persons who need intensive support to live at home. Without waiver services some persons would need care in a nursing home. If your young adult have a disability and require lots of help with personal care or supports, ask about the waiver services with the Georgia Department of Community Health, www.dch.georgia.gov/waivers . Your youth’s doctors, nurses, social workers, or care coordinators should be able to point you in the right direction. Waivers change so be sure the information is up-to-date.

Children’s waivers are different from those for adults. Eligibility for some waivers change based on age. If your young adult is currently receiving waiver services, find out if they “age-out” of their waiver program and what waiver programs are available for adults.

Services provided by waivers can include: personal care or attendant services, nursing care, therapy, home making, equipment and supplies, case management, minor home adaptations, and supports to help your young adult be a part of your community. Not all waivers provide the same services, so it is important to explore all of the waivers and see which would work best.

Just as there are different waivers, there are different eligibility requirements. There may be waiting lists to get on special Medicaid waivers. It is best to plan ahead and sign up early.

Children’s Health Insurance Program (CHIP) is a state and federal partnership that targets uninsured children and pregnant women in families with incomes too high to qualify for most state Medicaid programs, but often too low to afford private coverage. In most states the CHIP program provides health care services to children and teens **up to age 19**. For more information on Georgia’s *PeachCare for Kids* program, visit www.peachcare.org.

State Children with Special Health Care Needs Programs -Title V CSHCN. Each state combines federal and state funds to make sure there are comprehensive services for children with special health care needs. All states provide information and referral for diagnostic and treatment services and other resources. Some states provide direct services, such as specialty clinics, diagnostic screenings, care coordination and health care transition preparation. For more information on Georgia’s *Children’s Medical Services* program, visit www.dph.georgia.gov/CMS.

Medicare/ SSDI: Young people may qualify for Medicare through Social Security Disability Income (SSDI) because:

- they are “adult disabled children” of adult workers who have become disabled, retired, or deceased
- they have worked and paid into Social Security for two or more years and then become disabled. After receiving disability benefits for 24 months, they are eligible for Medicare.

INSURANCE SAVVY: THINGS YOU SHOULD LEARN

- Learn what services are covered under the insurance plan. Be clear about when coverage under that plan ends based on your young adult’s age and school status. Read the insurance handbook to learn about benefits and responsibilities; look for yearly open enrollment periods when a change of coverage is allowed.
- Adult Dependent Disabled Child. Some health insurance plans include a permanent dependent status for adult children who are dependent on family for care and finances. Often this means that

the young adult is on SSI or meets the SSI disability definition, is not working full time, and lives at home. Sometimes there is only one time or one age they can apply. If you miss that time or age, your family can never apply again. Find out if this status applies to you and plan ahead.

- Use providers covered by your insurance plan and know if the primary care provider needs to refer you to specialists. If providers in the network are not used, a bill might be in the mail!
- Ask the doctor/nurse practitioner to prescribe medications on the discount lists at major pharmacies whenever possible. If paying for medication is a hardship, ask the doctor for a referral to special programs through drug companies or other organizations that help those who cannot afford their medications. These programs may be called Prescription Assistance Programs.
- Most insurance companies have case managers who can work with those who have special health care needs. Ask for their help if needed. Their role is to help you get the services and resources you need through the insurance company.
- Keep good records including bills, receipts and letters from your health care insurer. Document all your phone calls, faxes, and emails. Be sure to include the name of the person you talked with.
- Insurance companies don't pay unless something is "**medically necessary**". Tell your doctor or other health care professionals why you need a medication, service, or equipment so they have a clear picture of what is needed and why it makes a difference in your child's health and quality of life.
- Find ways to pay if the insurance doesn't. Plan a payment schedule. Ask the doctor, clinic, public health department, or hospital about Patient Financial Assistance Programs. Explore special community, church, or non-profit organizations that might help with the payment. Your young adult can find an advocate to help them figure things out.

WHAT IF YOUR YOUNG ADULT IS WITHOUT INSURANCE?

First, reassure your young adult to not neglect their health care needs if they lose their insurance. There are resources out there, but you sometimes have to dig to find them. Second, encourage your young adult to talk with a social worker, care coordinator, or advocate who knows the resources in their area. These professionals can help them find public clinics that provide free health care or use a sliding scale based on income, such as the local health department and federally funded primary care centers.

Churches, the Salvation Army, or other private organizations provide free health clinics in some communities.

ADDITIONAL INFORMATION

PARENT'S/CAREGIVER'S TRANSITION WORKSHEET

This worksheet is to assist in the planning for your youth's transition to adulthood. Please check the boxes below that apply at this time. After this worksheet is complete it should be used to assess what needs to be done for transition.

HEALTH CARE	
<input type="checkbox"/> I understand my youth's medical condition.	
I have planned for my youth's:	
<input type="checkbox"/> Adult specialty medical care	<input type="checkbox"/> Vision Care
<input type="checkbox"/> Adult primary medical care	<input type="checkbox"/> Guardianship
<input type="checkbox"/> Adult dental care	
<input type="checkbox"/> My youth is unable to care for self	
My youth is able to:	
<input type="checkbox"/> Describe his/her medical condition	<input type="checkbox"/> Manage medications
<input type="checkbox"/> Perform daily medical care/treatments	<input type="checkbox"/> Advocate for self
<input type="checkbox"/> Consent to medical care	<input type="checkbox"/> Refill medications and supplies
<input type="checkbox"/> Make medical appointments	
<input type="checkbox"/> Understand his/her insurance coverage	
FINANCING	
As an adult, my youth's medical care will be paid for by:	
<input type="checkbox"/> Private health insurance through employment	
<input type="checkbox"/> Family's private health insurance	
<input type="checkbox"/> Medicaid	
<input type="checkbox"/> Medicare	
<input type="checkbox"/> Trust/Will	
<input type="checkbox"/> None of these apply	

Adapted from The University of Illinois at Chicago, Division of Specialized care for Children

HEALTH CARE TRANSITION CHECKLIST (AGE 12-15)

This checklist is to assist in the planning for your youth's transition to adulthood.

Age 12 – 15		Things my child needs to know or do.	Will someone else have to do this for my child? (Yes or No)	I will finish by (date)	Done
My child understands his/her health care needs.	Y N		Y N		
My child explains his/her special needs to others.	Y N		Y N		
My child tells the doctor how he/she is doing and can answer his/her questions.	Y N		Y N		
My child knows the name of his/her doctor(s).	Y N		Y N		
My child takes his/her medicine with supervision.	Y N		Y N		
My child knows the name(s) of the medicine he/she takes and possible side effects.	Y N		Y N		
My child knows when he/she is sick.	Y N		Y N		
My child carries a copy of his/her insurance card.	Y N		Y N		
My child carries a summary of his/her medical information with him/her.	Y N		Y N		
My child is learning to schedule his/her own appointments.	Y N		Y N		
We are reviewing eligibility for adult services and when to apply.	Y N		Y N		
We are investigating obtaining a Medical Power of Attorney.	Y N		Y N		
Before a doctor's appointment, my child prepares written questions to ask.					

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HEALTH CARE TRANSITION CHECKLIST (AGE 15-18)

This checklist is to assist in the planning for your youth's transition to adulthood.

Age 15 - 18		Things my child needs to know or do.	Will someone else have to do this for my child? (Yes or No)	I will finish by (date)	Done
My youth manages his/her doctor visits, explaining any problems and concerns.	Y N		Y N		
My youth knows he/she can meet alone with his/her doctor for part of the visit.	Y N		Y N		
My youth keeps a record of his/her appointments and knows the reason for them.	Y N		Y N		
My youth calls the doctor to schedule or reschedule appointments as needed.	Y N		Y N		
My youth takes his/her medicine and does treatments as scheduled.	Y N		Y N		
My youth takes part in making medical decisions.	Y N		Y N		
My youth informs family of when medicine needs to be ordered or calls in his/her own refills.	Y N		Y N		
My youth has talked with his/her doctors about choosing a doctor for adult care when he/she turns 18.	Y N		Y N		
My youth knows about his or her health insurance and how it works.	Y N		Y N		
My youth is learning what health insurance coverage he/she will have when he/she is 18.	Y N		Y N		
We have started talking about moving from pediatric to adult health care providers.	Y N		Y N		
My youth assists with filing his/her medical records and receipts at home.	Y N		Y N		

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HEALTH CARE TRANSITION CHECKLIST (AGE 18-21)

This checklist is to assist in the planning for your youth's transition to adulthood.

Age 18 – 21		Things my child needs to know or do.	Will someone else have to do this for my child? (Yes or No)	I will finish by (date)	Done
We are establishing a Medical Power of Attorney and/or Guardianship.	Y N		Y N		
The transition to adult health care provider is on-going.	Y N		Y N		
We have applied for Social Security Insurance (SSI).	Y N		Y N		
We have contacted our private insurance plans about coverage.	Y N		Y N		
We are aware that some services may end.	Y N		Y N		
My youth co-signs the "permission for medical treatment" form (with or without signature stamp).	Y N		Y N		
My youth knows symptoms that need quick medical attention.	Y N		Y N		
My youth knows what to do in case of a medical emergency.	Y N		Y N		
My youth helps to monitor and maintain medical equipment by doing daily/routine services.	Y N		Y N		

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PLANNING FOR HEALTH CARE TRANSITION: ACTIVITIES TO CONSIDER

TASK	ACTIVITIES
Develop maintenance plan for Durable Medical Equipment	<ul style="list-style-type: none"> a. Wheelchair servicing b. Wheelchair replacement c. Warranty information on other equipment
Develop supply ordering schedule	<ul style="list-style-type: none"> a. Vendor information b. Supply information c. Frequency d. Quantity e. Delivery method
Find adult health coverage for youth	<ul style="list-style-type: none"> a. Find out requirements for “Adult Disabled Dependent” coverage b. Review other commercial insurance plan coverage options c. Apply for Medicaid for primary coverage of supplemental coverage if needed
Complete portable medical record summary	<ul style="list-style-type: none"> a. Obtain information b. If there are lots of medical records, be selective and request discharge summaries from hospitalizations and the past 2 – 3 years of progress notes including labs and x-rays. c. Share responsibility for gathering information
Create wallet emergency information and medication care	<ul style="list-style-type: none"> a. Emergency contact information b. Allergies and drug interactions c. Medication list d. Pharmacy information e. Physician information f. Communication method g. If you child has a cell phone, enter in your ICE (In Case of Emergency) contacts. First responders such as paramedics, firefighters, and police officers look in cell phone address books under ICE for people who can provide important medical information when the person they are helping cannot. Make sure the ICE contacts know your child’s “MAD” – Medicines, Allergies, and Doctors.
Complete reproductive counseling	<ul style="list-style-type: none"> a. Safe sex b. Family planning c. Genetics
Transition to adult health care providers	<ul style="list-style-type: none"> a. Primary care b. Specialty care (e.g. Gynecology, Cardiology etc.) c. One way to help the new adult primary care provider get “up to speed” is to prepare a medical summary d. Talk with family and other health care professionals about the providers and services your youth will need as they become an adult
Apply for SSI	

Comprehensive Care Planning – Health Care Transition Action Plan

Youth's Name:

Primary Diagnosis:

Original Date of plan:

Main Concerns/Goals	Current Plans/Action	In Process	Date Complete

Got Transition? National Health Care Transition Center

©Center for Medical Home Improvement 1/17/2011

Health Care Transition Summary

Name _____ DOB _____ SS# _____
 Address _____
Street City State Zip
 Phone _____
Home Work Cell
 Emergency Contact: _____ Relationship: _____ Phone: _____
 Guardian/Health Surrogate: _____ Relationship: _____ Phone: _____
 Unique Communication/Cultural Needs: _____
 Strengths/Assets: _____
 Assistive Technology: _____

Primary Insurance: _____
Policy # Case Manager Phone #
 Secondary Insurance: _____
Policy # Case Manager Phone #
 Allergies: _(meds & food) _____
 Recent Lab, X-ray Findings: _____
 Height: _____ Weight: _____ Dietary/Nutritional Needs: _____
 Primary Care Provider: _____ Phone: _____
 Address: _____
Street City State Zip

Diagnosis	Managing Provider/ Specialist	Address	Phone
1.			
2.			
3.			
4.			
5.			

Current Medications	Current Medications
1.	5.
2.	6.
3.	7.
4.	8.

Current Therapies	Frequency	Provider	Contact Information
1.			
2.			
3.			

Medical Equipment	Medical Supplies	Provider	Contact Information
1.			
2.			
3.			
4.			

Orthotics & Prosthetics	Provider	Contact Information
1.		
2.		

Past Hospitalizations (including surgeries)			
Date	Hospital Name	Reason	Physician

Functional Capabilities	Brief Summary
Upper Extremities	
Lower Extremities	
Speech/Language	
Cognitive/ Problem Solving	

Future Plans (including agencies involved & referral made)
Health Care
Health Insurance
School & Work
Independent Living (housing, transportation, attendant care)

Services Currently Receiving	Provider Contact Information
1.	
2.	
3.	
4.	

Taking Charge of Your Health Care: A handout for adolescents and young adults with special health care needs and disabilities

Be your own health care advocate

- Learn about your condition or disability.
- Know the warning signs that mean you need emergency help.
- Know who to call in case of an emergency. Carry that information with you.
- Learn how to make your own appointments.
- Write down any questions you have before you go the doctor's office.
- Meet privately with your doctor/nurses and others.
- Speak up and ask your doctor or nurse questions. If you don't understand an answer, ask again.
- Talk to your doctor about difficult topics such as relationships, drugs, and birth control.
- Tell your doctor if you are feeling down. Your doctor can suggest people to talk to.
- Ask your doctor to explain all tests and their results.
- Ask for copies of medical tests or reports.
- Carry your insurance card and other health care information that you think is important.

Take charge of your health care information

- Be sure to understand the medications that you are taking. What are their names and when do you take them?
- Know how to call your pharmacy and how to fill your prescriptions.
- Make sure you know your insurance and how to get a referral.
- Keep a list of addresses and telephone numbers of all your doctors and nurses.
- Keep a notebook of your doctor reports, medications, operations and results of medical tests.
- Ask your doctor for a short written summary of your health condition.
- Know how to order and take care of any special equipment you use.

Plan for transfer to an adult doctor

- Talk to your doctor about how and when you should start seeing an adult doctor.
- Discuss with your doctor resources that might be helpful to you.
- Meet and talk with the new adult care doctor before you switch.

Keep yourself healthy, exercise, and eat a good diet...

RESOURCES

1. Georgia Department of Public Health, Children's Medical Services, <http://dph.georgia.gov/cms>
2. *Got Transition*, National Health Care Transition Center, <http://www.gottransition.org/>.
3. Parent to Parent of Georgia, www.p2pga.org.
4. Healthy Transitions NY, www.healthytransitionsny.org. This site has some helpful, easy to understand videos that you could watch with your child. It was developed by the New York State Institute for Health Transition, Training for Youth with Developmental Disabilities. The videos help walk your child through the process of getting an appointment or how to speak up at a doctor's office. The website has more than 40 videos on various health transition related skills.
5. DisabilityInfo.gov: www.disability.gov. This federal web site links to information of interest to people with disabilities and their families. Topics include employment, education, housing, transportation, health, income support, technology, community life, and civil rights.
6. GovBenefits.gov: www.govbenefits.gov. A partnership of federal agencies and organizations with enhanced access to government assistance programs. There is a confidential online screening tool that can help individuals find out which government programs and benefits they may be eligible to receive.
7. Healthy and Ready to Work National Resource Center, <http://www.syntiro.org/hrtw/>

CREDITS/ACKNOWLEDGEMENTS

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4. Transition Planning Workbook, Hilopa'a Style 1.1. Family Voices of Hawaii. Department of Health Children with Special Needs Branch.
5. Transition to Adult Services. Family Resources 4/05. www.michigan.gov/documents/transition_timeline2.
6. Moving Into Adult Health Care, What do Parents Need to Know? A guide for parents of young adults with and without disabilities. Connecticut Edition, 2012. Connecticut Department of Public Health. Family Health Section. CYSHCN Program.
7. Ten Steps to Health Care Transition. Maryland Department of Health and Mental Hygiene Office for Genetics and Children with Special Health Care Needs.
8. Comprehensive Care Planning – Health Care Transition Action Plan. Got Transition? National Health Care Transition Center.