



What's **Health**
got to do with **Transition?**



*Moving from
pediatric to adult
health care*





What's inside

Transition to adulthood is a time of change. It is also a time of preparation. While many teens and their families prepare for transition to college or a career, they may not think about planning for change in health care. They might not realize that there are many complex issues that take time to learn about, particularly if the youth has special health care needs. This guide provides important steps and tools to help young people – from preteens to young adults - and their families prepare for the transition from pediatric to adult health care.

“What’s Health Got To Do with Transition?” and “Health Impacts All Aspects of Life” adapted from the Maternal and Child Health Bureau, Healthy & Ready to Work National Center.

INDEX

10 steps towards successful health care transition:

Section		Page
1	 Plan for change	3
2	 Pediatric vs. adult health care	5
3	 Paying for health care	6
4	 Age 18 in legal terms	9
5	 Health-related skills	10
6	 Finding adult providers	12
7	 Communicating effectively	14
8	 Medical summary	16
9	 Support from schools	19
10	 Identify resources	20

HEALTH IMPACTS ALL ASPECTS OF LIFE!

Success in the classroom, within the community, and on the job requires that young people stay healthy. The best way to stay healthy is for each person, as developmentally able, to understand their health and participate in health care decisions.

What does “health care” really mean for a teen? Many have never thought about it because someone else usually handled those issues. Young children are often covered on their parents’ health insurance plans or through public assistance programs, or perhaps even a combination. Health services are typically received in a pediatric office or with a specialist.



This guide offers tools that can be used by teens, families, and providers to ensure a smooth transition from pediatric to adult health care.



But what happens after a teen turns 18 and is legally an adult? At what point are his or her medical needs better served by an adult provider? How and when should youth learn about these things?

These are complex issues that take time to learn. Teens and young adults need to be taught health-related skills. They need to be shown how to make informed decisions that are based on accurate information. An atmosphere that encourages independence and self-determination can help lead youth to productive adulthood. On the other hand, lack of direction and support may result in confusion, doubt, and little initiative.

This guide offers tools that can be used by teens, families, and providers to ensure a smooth transition from pediatric to adult health care. There is a lot of information in the guide, so it may seem overwhelming or complicated at first. It might be helpful to ask a health care provider about items that are hard to understand or confusing. Because the guide is designed for all youth, including those with disabilities and special health care needs, families may also find that some items don't apply to their situation. Use what is helpful, hang on to the guide, and refer back to it as needed. Information that does not seem useful right now may become important at a later time.

Teens who learn how to manage their own health are able to live more independently.

PLAN

A photograph showing a man and a young man sitting at a desk. The man, wearing a purple t-shirt, is leaning over the desk, pointing at an open book with a yellow pencil. The young man, wearing a grey t-shirt and a grey beanie, is looking down at the book and holding a yellow pencil. The scene is brightly lit, suggesting an indoor setting like a classroom or library.

PLAN FOR CHANGE

IT MAKES A DIFFERENCE!

1

Taking responsibility for one's own health care is part of growing up, becoming independent, and finding a place in the adult world. Planning for transition to adult health care can teach life-long skills for getting important services.

Children and teens, as developmentally able, need to understand their medical condition, medication, and health insurance. They need to learn how to communicate with their doctors, make appointments, and make informed health decisions. Parents and caregivers need to learn about changes in health care needs, services, and insurance coverage as youth transition into adulthood.

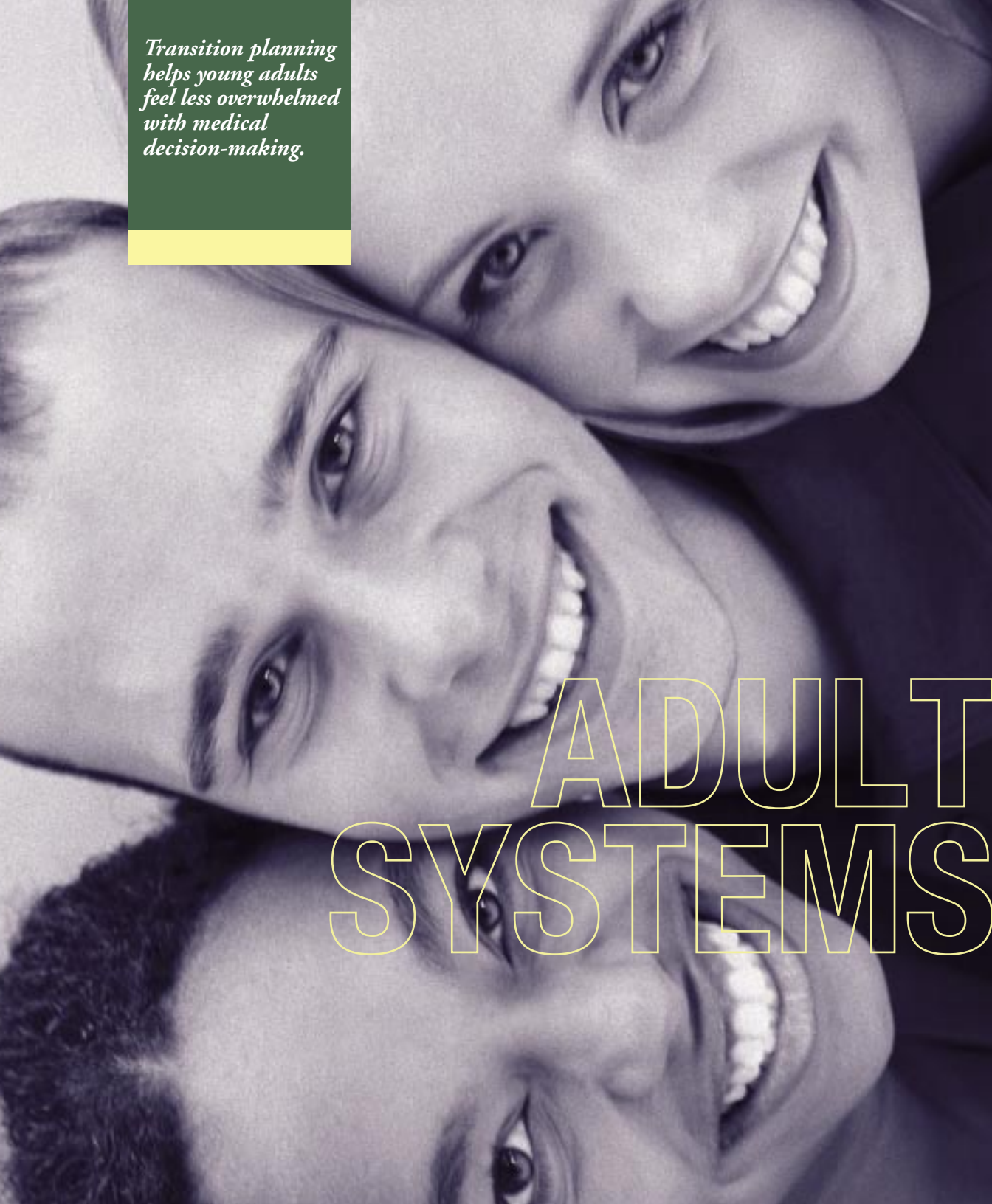
Youth with Special Needs

For young people with special needs, these issues are particularly important. Age-appropriate health care services are essential for reducing the risk of secondary disabling conditions. Teens who learn how to manage their own health care are able to live more independently. But teens with disabilities often face additional challenges in this step towards adulthood. They may find it hard to find an adult provider who is trained in pediatric or developmental conditions, and is willing to assume primary responsibility for their care. Or, teens who already receive care from a family physician may find it easy to continue in a child's role rather than take on an adult role. Either way, young people may be uncomfortable in the role of adult health care consumers, and families may have trouble letting go.

Create a Written Plan

Pediatricians and other service providers can play an important role in providing information and direction to youth and families on issues affecting health care and lifestyle choices. It is helpful to begin planning by writing down future goals and then identifying the things that need to be done in order to achieve those goals. Several checklists and suggestions are provided in the following pages, and can be used to develop a written plan. ***Successful transition requires that youth, family, doctors, and other providers all work together to plan for needed skills and services, ways to get the services, and methods of paying for them.***





*Transition planning
helps young adults
feel less overwhelmed
with medical
decision-making.*

ADULT SYSTEMS

UNDERSTAND HOW ADULT SYSTEMS

DIFFER FROM PEDIATRIC HEALTH CARE SYSTEMS

2

Anxiety can result when youth and families are unprepared for dealing with the adult medical world.



Pediatric practices are usually family-friendly and informal. Nurses and other staff are very involved in providing care, and parents are encouraged to participate.

On the other hand, adult systems are more business-like and formal. The emphasis may seem to be on the disease rather than the person. Services are usually provided by a single physician and require less involvement by nurses and staff. Adult health care consumers are expected to communicate directly with doctors, understand and follow through with treatment plans, and make their own decisions.

Anxiety can result when youth and families are unprepared for dealing with the adult medical world. The new situation may create uncertainty about knowing what to do, understanding what is appropriate, feeling accepted, and trusting the knowledge of the new provider. At the same time, youth may have feelings of grief or loss for their pediatrician, or may even think of the change as punishment or rejection. Transition planning can help young adults feel less overwhelmed with their new responsibilities for medical decision-making, and can help families avoid feeling alienated.

KNOW ABOUT PAYING FOR HEALTH CARE

3

AND INSURANCE IN ADULTHOOD

Young adults with special health care needs often require insurance that covers a broad range of services.

As youth age out of health care plans and services, they face eligibility changes for private insurance, state children's insurance programs (Florida KidCare), Medicaid, and other publicly funded programs. Under most insurance plans, a variety of conditions must be met in order to keep coverage. Young adults with disabilities or chronic illnesses often have special problems accessing health insurance, particularly if they are no longer covered by their parents' insurance. A desire to work and be independent may also jeopardize the young person's "dependent child" status that is required to remain on a parent's health plan.

Young adults with special health care needs often require insurance that covers a broad range of services. That may include multiple medical consultations, laboratory tests, equipment, and prescription plans. Adequate insurance is not easily available to many workers with disabilities, who may be forced to accept part-time or lower wage jobs that don't provide full health care benefits.

Generally, insurance coverage for therapies that are important to a disabled person's mobility, communication, and other functions often are not provided, or provided only for a very limited number of hours per year. Ultimately, inadequate health care benefits can limit an individual's ability to work.



There are a variety of programs available that may help pay for health care in the transition to adulthood. Many programs use complicated formulas to determine eligibility. Sometimes programs change eligibility requirements and the change is not reflected in their written materials. **Applying** is the best way to find out whether someone is eligible.

Also, many private "charitable" programs require proof that an individual has been rejected by government programs before they will consider helping that person. If a government program application is rejected, find out why. Is it due to missing paperwork, too high income, or something else? Decisions can usually be appealed within a specific time frame. It is often beneficial to ask elected officials for help in appealing a written denial. ***Do not accept "no" the first time ... file an appeal!***



Private Insurance

If the youth is covered by private insurance (such as parents' insurance from work), parents need to find out how long the child can stay on the family policy. This depends on where the parent works, the child's age, whether or not the child is in school, and whether or not the employer allows a "dependent child" with a disability to stay on the health plan after age 18 or 21. Find out how the insurer handles referrals and consultations for transition to adult health care.

If the youth is planning to work, he or she needs to find out if the job offers health insurance. If insurance is offered, then the youth and family need to determine which plan to select. Find out how much it will cost each month and if the physicians, hospitals, and other health care providers you want are covered by the plan.



Medicaid

Youth with special needs who are covered by Medicaid need to reapply when they turn age 18 to see if they can continue their coverage. If they are not already covered, they may be eligible to sign up for Medicaid at that time. Parents' income is not counted once the child turns 18. Eligibility will count only the young adults' income and assets such as bank accounts and property (if there are any). Many programs for adults with disabilities require the participants to be on Medicaid. Some families find it necessary to access Medicaid because their children no longer meet the age or dependent status criteria of their private insurance.

If the young adult is planning to go on Medicaid at age 18, ask his or her doctors if they accept Medicaid (they do not have to do so). If not, ask them for names of doctors and clinics who accept Medicaid. If a young adult receives Medicaid and also gets a job, it is very important to find out how much someone is allowed to earn and still stay on Medicaid.

Young adults with severe disabilities or chronic health needs may be eligible for SSI (Supplemental Security Income) from the federal government. In Florida, SSI beneficiaries automatically receive Medicaid benefits. If a child already receives SSI benefits, he or she must reapply at age 18. ***It is important to know that SSI eligibility guidelines for adults are different than those for children. A child who receives SSI will not automatically receive those benefits as an adult.***

There are also several Medicaid Waiver programs available in Florida for which the youth may be eligible, such as the Agency for Persons with Disabilities Home and Community-Based Waiver (formerly called Developmental Services Medicaid Waiver), or the Medicaid Medically Needy Program. ***Some programs have waiting lists, so it is important to apply as early as possible.*** Call your local SSI and Medicaid offices for more information about these programs (see resource listings).

It's important to remember that rights are precious, and should not be removed unless it is in the best interest of the young adult.

GUARDIANSHIP

A young woman with Down syndrome is sitting at a desk, looking at a laptop. She has a thoughtful expression. She is wearing a maroon long-sleeved shirt. The background is a bright window with greenery outside. The text 'GUARDIANSHIP' is overlaid in large white outline letters across the middle of the image.

When youth turn 18, they are considered adults and are legally able to make all of their own decisions. At that point, parents are not asked for permission and have no legal right to speak for their child.

UNDERSTAND WHAT AGE 18 MEANS IN LEGAL TERMS

4

At age 18, youth are responsible for making decisions about medical treatments such as medications and surgeries, where to live, whether or not to continue school, and signing financial and legal documents. It is no different for a teen who has special health care needs or a developmental disability. For young people who are capable of making informed choices when presented with complex issues, this is just as it should be.

In some situations, young adults may need assistance in making decisions. There are several levels of assistance to consider, from having family and friends provide informal guidance and support, to appointing a legal guardian through the court. Regardless of the level of disability, all young adults ultimately have the right to make their own decisions unless a court has declared differently.

Guardianship

Guardianship is a legal arrangement where an individual is formally declared to be “incompetent” or unable to make certain decisions for themselves. The court appoints another adult to make such decisions. The appointed guardian is often a family member, but the guardian can also be a trusted friend or from a public guardianship agency. Guardianship can be shared between co-guardians and it can also be temporary. While some young adults may need a guardian to make virtually all decisions (*full guardianship*), others may need guidance only in certain parts of their life (*partial guardianship*).

Other Alternatives

Guardianship is not the only way to protect a young adult’s health interests. Less restrictive alternatives include appointing a *Health Surrogate* (called an “advance directive” in Florida) or establishing *Power of Attorney* (the young adult gives someone else the right to make medical decisions). Each directive has very specific guidelines and limitations in power, so it is important to understand the scope of action. Some health care directives can be obtained online or from a medical facility, and can be established without hiring an attorney. Increasingly, doctors and hospitals are requiring that legal documentation regarding medical decision-making be presented prior to providing services to individuals who appear to have cognitive impairment. It’s better to make decisions about these issues before an emergency!

It is important to remember that rights are precious, and should not be removed unless it is in the best interest of the young adult. If parents feel their child will need assistance in making health-related decisions, they should explore the different options regarding guardianship with an advocacy organization or attorney (see local listings in the last section of the guide under “Guardianship”). If guardianship is appropriate, an application must be submitted through the county probate court. *Guardianship does not happen automatically, and it’s not free!*

PRACTICE HEALTH-RELATED SKILLS

ACCORDING TO AGE & DEVELOPMENTAL ABILITIES

5

Skills and information should be introduced and supported by the pediatric provider and family in stages according to age and developmental ability. A transition checklist of issues and actions might look like this:

Early Transition Stage (10-12 years/Grades 5-7)

CHECK LIST

- ✓ **Communication.** Begin helping youth to interact directly with doctors, nurses, and therapists. Encourage questions during each office visit.
- ✓ **Daily schedules.** Discuss daily medications and treatments, including problems or barriers to compliance.
- ✓ **Medical emergency.** If youth wears a Medical Alert ID bracelet, discuss its purpose and how to seek help. Carry a portable medical summary (see page 16).
- ✓ **Fitting in.** Talk about social activities, peer involvement, and caring relationships. Discuss health-related restrictions (real or imagined) on educational or recreational activities. Ask about problems with bullying in school or the community.
- ✓ **Risky behaviors.** Talk about smoking, use of alcohol and street drugs. Discuss the impact of risky behaviors on the youth's health condition and general well-being.
- ✓ **Medical condition.** Assess perception and basic knowledge of his or her special needs. Build on youth's current understanding.
- ✓ **Self-care skills.** Continue teaching general self-care skills as well as skills related to his or her special needs.
- ✓ **Sexuality.** Discuss puberty changes, differences from peers, and impact on health condition. Introduce information about sexuality.
- ✓ **Exercise.** Discuss the importance of regular exercise. Encourage participation in recreational activities.
- ✓ **Self-esteem.** Discuss issues of body image, concerns with dieting, exercise, weight gain or loss.
- ✓ **Preparing parents.** Parents should talk to their pediatrician about loss of control, concerns about the future, and ways to increase youth's independence.

Middle Transition Stage (13-15 years/Grades 8-10)

CHECK LIST

- ✓ **Access to information.** Discuss strategies to access information about condition and treatments (such as support groups, Internet, library, condition-specific associations).
- ✓ **Health management skills.** Let teen make doctor appointment and talk with receptionist. Encourage teen to be in the exam room without family, learn about medication, and practice calling in prescription refills.
- ✓ **What to do in an emergency.** Discuss when, how, and from whom to seek help in emergency situations such as during a fire, bad weather, or loss of electricity.
- ✓ **Transportation.** Discuss plans for driving; identify any restrictions or need for adaptive equipment. Learn how to use public transportation.
- ✓ **Sexuality.** Talk to teen about dating, sexuality, gender preference, and masturbation.
- ✓ **Peer pressure.** Continue to encourage teen to talk about smoking, alcohol/drugs, body image, and problems with bullying. Discuss ways to deal with social pressure.
- ✓ **Mental health.** Provide opportunities to discuss feelings of depression or suicidal thoughts.
- ✓ **Emotional support.** Have teen identify person(s) to contact for help or advice with these feelings.

Late Transition Stage (16-21 years/Grades 11-12)

CHECK LIST

- ✓ **Adult providers.** Begin - *with the teen*- looking for an adult primary care provider. Explore choices and meet with adult providers before discontinuing pediatric care. Finalize transfer of medical care to adult provider between ages 18 and 21.
- ✓ **Health insurance.** Discuss current and future medical coverage. Practice using insurance card and filling out patient forms at doctor visits.
- ✓ **Health records.** Help teen maintain personal health record book to keep track of medical and dental appointments, health information and history, medications and treatment, and all health care providers (including names and telephone numbers).
- ✓ **Sexual health.** Discuss sexual health, including genetic risks, sexual capabilities, fertility, and sexual vulnerability.
- ✓ **Career/employment.** Discuss post secondary education, career training, and employment options. Do plans conflict with health needs? What supports are needed?
- ✓ **Personal supports.** Identify needs for employment, personal assistance in care, issues of living away from family, transportation.
- ✓ **Adult programs.** Check eligibility and application guidelines for adult programs such as Vocational Rehabilitation and SSI *before* teen turns 18. ***Gather required medical reports and apply for programs early!***
- ✓ **Mental health.** Continue to discuss feelings of depression, and persons to contact for help or advice. Get information on short-term and long-term mental health support.

SKILLS

FIND AND USE

6

ADULT HEALTH CARE PROVIDERS

As young adults get older, their health care needs change. Youths need regular screenings for medical conditions that may appear in adulthood, such as high blood pressure, breast cancer, testicular cancer, cardiovascular disease, and sexually transmitted diseases.

For young people with disabilities, age-appropriate care is particularly important in order to reduce the risk of secondary disabling conditions. *Getting the right preventive care means staying healthy longer!*

Pediatric providers and family members need to discuss how the teen's health care needs are changing, and determine together when it is the right time to transition to an adult setting. Many pediatricians stop service to teens between the ages 18 to 21. Here are some suggestions on how to find and use adult health care providers.



Choose a primary care doctor who works with adults. Ask for a referral from:

CHECK LIST

- ✓ **Pediatrician.** Ask your pediatrician or specialist for a referral to a primary care physician who is sensitive and knowledgeable about specific health needs and disabilities.
- ✓ **Insurance company.** Call your insurance company to get a list of doctors on their provider list. Ask to speak to the nurse coordinator and share your situation; he or she may be helpful in identifying appropriate physicians.
- ✓ **Support group.** Call associations or support groups for specific health conditions and ask if they can recommend a doctor.
- ✓ **Friends.** Talk to friends who have similar health conditions. Ask them who their doctors are and whether they like them.

Once you have a list of doctors, call each doctor's office. Ask the office manager or receptionist about:

CHECK LIST

- ✓ **Openings.** Are they accepting new patients?
- ✓ **Insurance.** Do they accept your insurance?
- ✓ **Accessibility.** Can they meet your special needs, such as accessible parking or bathrooms?
- ✓ **Interpreters.** If you use sign language or speak a language other than English, do they have interpreters available?
- ✓ **Location.** Where is the office located? What are the days and hours the office is open?

Ask the nurse or doctor about:

CHECK LIST

- ✓ **Experience.** Do they have experience working with patients with a specific medical condition?
- ✓ **Hospitals.** What hospital does the doctor use, and who will provide care in the hospital?
- ✓ **Medical records.** If possible, bring copies of your medical records to your visit. If not, you will need to bring contact information for all of your doctors so that the new doctor can get copies of your medical records.
- ✓ **An interview.** Consider scheduling a short interview with potential doctors. Once a new doctor is chosen, be sure to visit him or her at least once before the last visit with the pediatrician.

Find an adult specialist if you need one. Ask for a referral from:

CHECK LIST

- ✓ **Pediatric specialist.** Ask your pediatric specialist for a referral.
- ✓ **Insurance company.** Call your insurance company. Ask if you need to get a referral from your primary care physician before you can see a specialist.
- ✓ **Adult primary care doctor.** Tell your new adult primary care physician if you need a referral to a specialist. Ask him or her for a list of specialists.

Most pediatric providers can help their patients transition to appropriate adult care. However, some physicians are not knowledgeable about issues unique to youth with chronic conditions and disabilities, or are not comfortable dealing with sensitive issues that emerge during teenage years. In these situations, they may prefer to refer their patients to a provider that specializes in adolescent health care.

In Hillsborough County, some youth are referred to the *University of South Florida Adolescent/Young Adult Program* by their pediatrician specifically for transition-related services and referral to adult health care providers. Listings for the USF program and several local adult primary care physicians can be found in the last section of the guide.

LEARN HOW TO COMMUNICATE *EFFECTIVELY WITH PROVIDERS*

7

Talking to doctors and other health care providers can be difficult, overwhelming, and sometimes scary.

But research shows that patients who are active members of their own health care team tend to be more satisfied with their care – and have better results. Here are some tips on how youth and families can establish effective communication with their health care providers.



Give information. Don't wait to be asked!

CHECK LIST

- ✓ **Be open.** You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know.
- ✓ **Be honest.** It's important to tell your doctor personal information—even if it makes you feel embarrassed or uncomfortable.
- ✓ **Have an updated medical summary.** Bring a medical summary with you, and keep it up to date. You might want to make a copy of the form for each member of your family (see sample medical summary on page 17).
- ✓ **Tell about vitamins and alternative medicines.** Tell your doctor about any herbal products or alternative medicines/treatments you use.
- ✓ **Know medications and allergies.** Always bring any medicines you are taking, or a list of those medicines. Include when and how often you take them, and what strength. Talk about any allergies or reactions you have had to your medicines.

Get information.

CHECK LIST

- ✓ **Bring a friend.** You might want to bring someone along to help you ask questions. This person can also help you understand and/or remember the answers.
- ✓ **Prepare ahead of time.** Write down your questions before your visit. List the most important ones first to make sure they get asked and answered.
- ✓ **Bring a tape recorder.** Most doctors don't mind if you bring a tape recorder to help you remember things, but ask first!
- ✓ **Let your doctor know if you need more time.** If there is not time that day, perhaps you can speak to a nurse or physician assistant on staff. Or, ask if you can call later to speak with someone. It helps to let the office know if you think you will need more time than the usual 10-20 minute visit when you make the appointment.
- ✓ **Ask for pictures.** Ask your doctor to draw pictures to help explain something.
- ✓ **Ask questions.** If you don't, your doctor may think you understand everything that was said.

Take information home.

CHECK LIST

- ✓ **Ask for written instructions.**
- ✓ **Ask for materials to take home.** Your doctor or nurse may have brochures, audio tapes, or videotapes that can help you. If not, ask how you can get such materials.

Once you leave the doctor's office,
follow up.

CHECK LIST

- ✓ **If you have questions, call!**
- ✓ **Call if you have problems.** If your symptoms get worse, or if you have problems with your medicine, call.
- ✓ **Find out test results.** If you had tests and do not hear from your doctor, call for your test results.
- ✓ **Get referrals for specialists.** If your doctor said you should see a specialist, make an appointment.
- ✓ **Get referrals for labs or tests.** If your doctor said you need to have certain tests, make appointments at the lab or other offices to get them done.



COMMUNICATE

DEVELOP A MEDICAL SUMMARY 8

A medical summary is a form that has a person's medical history and important contacts on one sheet of paper.

This is helpful when you need to share medical information or need a provider's contact information. It can be handed to a new doctor or to medical staff in an emergency situation so that the provider can quickly focus on the person's health status and needs. It is particularly useful if the individual has a complex medical condition or is unable to explain his or her needs. A portable medical summary is a valuable tool for anyone to use when visiting a new provider. For people who may not be able to communicate during a medical crisis, it can be a life-saver. The summary also may be used as documentation when requesting benefits or applying for public assistance (such as SSI).

The summary should be short - only one or two pages long - but concise and comprehensive. ***It should include contact information, birth date, social security number, physicians, preferred hospitals, diagnosis, current medications, allergies, therapies, equipment and supply needs, functional limitations, health surrogate or guardian (if applicable), insurance plan, and any common problems or issues.*** The summary should be easily accessible in an emergency situation. Some people carry these in their wallets and keep a copy in the car. It also is a good idea to provide copies of the form to family members or close friends.

While there are many different formats that can be used, the medical summary on the following page is an excellent example of a single page form. This form and other samples can be downloaded from the Healthy & Ready to Work Web site at www@hrtw.org. Just go to "Tools & Solutions", then "Tools & Checklists" and look under "Care Plans." Youth and families may want to ask their doctor or other health care provider to help them set up a form with information that best meets their needs.



complete Quad (has sensation), only movement left index finger 10 cm
 Need to explain EVERY procedure, when possible, ask for consent prior to
 f unable to talk => one blink = yes / two blinks = no

The summary should be short, only 1 or 2 pages long, but concise and comprehensive.

PRIMARY DIAGNOSIS

NAME
 Address, Home Phone, Cell Phone, Email
DOB 5/24/73 **SS#** 289-XX-XXXX **ALLERGY:** Sulta Drugs, Adhesive Tape
Date Updated

- High intelligence (130 IQ), compliant patient, high tolerance to pain
 - Incomplete Quad (has sensation), only movement left index finger 10 cm
 - Need to explain EVERY procedure, when possible, ask for consent prior to doing
 - If unable to talk => one blink = yes / two blinks = no - Read his lips - OR - letterword board to direct his care.

PRIMARY DIAGNOSIS

- NEURO/MUSCULAR**
359 Muscular Dyst(335 1 SMA)
- RESPIRATORY**
V44 Trach, 518 B1 Respir Failure
489, Pneumo Org NOS
- GASTRO**
V44 1 Gastro Status
- ORTHOPEDIC**
T37 4, 754 89, 754 81
- UROLOGICAL**
752 51
- BLOOD TYPE**
- SPECIAL NOTES**

AGE: 30 **HEIGHT:** 4'3" (51inches) **WEIGHT:** 80lbs approx

Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, 3/74)
 incomplete quad (has full sensation), no functional movement
 Respiratory failure - trach and vent (901) Chronic RLL Atelectasis,
 Recurrent pneumonia (last hospitalization, 9/01)
 Respiratory insufficiency, poor residual functions and reserved capacities
 Decreased esophageal motility, s/p feeding gastrostomy tube (7/83)

Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips
 flexion contractures, spinal fusion (3/82 Lueke Rod), pectus excavatum
 Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr,
 Cystoscopy/left ureteral stent (10/01), IVP (6/99)
 A + (positive)
 IV: Porta Cath (10/24/01) RIS right clavicle (PC 0603880 - lot 36PH124)

MEDICAL

ACUPUNCTURE PHYSICIAN
Barbara XXXXX RN, AP, Ocala, FL
O: 352-xxx-xxxx

INTENSIVIST: Mehlin XXXX, MD, Ocala, FL
O: 352-622-xxxx

PULMONOLOGIST: Robert xxx MD, Gainesville, FL
O: 352-xxx-xxxx Bpr 352-xxx-xxxx

HOSPITAL North FL Regional Medical Center, Gainesville, FL
4/95, 1/97, 5/01, 9-10/01

IMMUNIZATIONS Flu 02 Pneumo 79, 01 Tetanus 85
DPT 73, 79 Measles 74 Mumps 74
TB 78, 87

ENTERAL Pulmocare (237ml) x 2 cans, nocturnal 70 ml/hr

MEDICATIONS

- Rx DAILY**
- Alprazolam (xanax) 0.5 mg QID
 - Aspirin-Child 81 mg 1 x
 - Temazepam 15 mg HS
 - DuoNeb 1 vial QID
- Rx MONTHLY**
- Thiamine 100 mg monthly
 - Cyanocobalamin 1000 mcg/ml monthly (B12)
- Rx PRN**
- Darvocet-N 200/5ml 45ml
 - Zithromax SUS PFIZ 1-2 tablets
 - Diphnoxylate/atropine

- HERBS / PROPS**
- Lymphatic 5 2X
 - Flu Balancing 10 2X
 - Respiratory 7 2X
 - Alertox-airborne 5 2X
 - - - Alertox 3 3x
 - - - Alertox 10 4x
 - Immune 6 2X
 - Acute Rescue 5 2X
 - Urinary 6 2X
 - Digestive 3 2X
 - Mucous 7 2X
 - Cell 4 2x
 - Muscular 8 2x
 - Integumentary 1 1p 2X
 - Er Cheng Tang

VENT / TRACH / O2

VENT - Pulmonic LTV 900

Breaths 05
 Total Volume 310
 Inspiration 1.1
 Pressure Support 13
 Sensitivity 02
 High 40
 Low 02

TRACH Shiley 6 cuffed (deflated)

SPEAKING VALVE:
Passy-Mur PMV007

OXYGEN 1.5 liters

INSURANCE

BlueCross BlueShield of Massachusetts

Primary Subscriber: xxxxx xxxxx
 BC/BS PPO Plan Code 200
 Customer service: 800-226-xxxx
 XXX XXXXXXXX 10 PPO

Secondary Subscriber: xxxxx xxxxx
 BC/BS Blue Choice Plan 2, POS Code 200
 Customer service: 800-222-xxxx
 XX XXXXXXXX 10

HEALTH SURROGATE

BC/BS Case Manager
 Health Vendor
 Home Nursing Agency
 Pharmacy

Debra XXXXXXXX
 Option Care
 House Calls
 Bitting's

800-392-xxxx ext. xx
 800-825-xxxx 352-373-xxxx
 352-xxx-xxxx acc'l. # xxxxx
 352-732-xxxx acc'l. # xxxxx

UPUNCTUR
 rbara XXXX,
 352- xxx -xxx

ENSIVIST: M
 352-622-xxxx


L DAILY
 Alprazolam (xana
 Aspirin-Child
 Temazepam
 DuoNeb

MONTHLY
 Thiamine
 Cyanocobalamin 10

K PRN
 Darvocet-N
 Zithromax SUS PFIZ
 Diphnoxylate/atropine

ueCross BlueShield of Massachusetts

BlueCross BlueShield of Massachusetts



*The best transitions
occur with a team
approach.*

SUPPORT

While skill-building may start during early childhood years, formal transition planning should begin by age 14.

SEEK SUPPORT FROM SCHOOLS AND OTHER COMMUNITY AGENCIES

9

For teenagers with disabilities who receive special education services, transition goals for employment, secondary education, and independent living are included in their transition IEP (Individualized Education Program). Planning meetings should be attended by the teen, family, teachers, providers, and community agencies that can support the teen's aspirations. Some youth direct these meetings themselves.

Health and medical issues are essential to all of these transition goals, yet they are often overlooked or given only a few minutes of attention during IEP or 504 Plan meetings. There are many health-related issues, skills, and activities that can be addressed when developing a school-based transition plan.

Students who have an IEP may choose to stay in school and receive free public education through age 21. After high school, some may be eligible to receive services from programs for adults with disabilities. However, many of these programs have long waiting lists. Families and youth who plan ahead have a much better chance of getting adult services. ***It's important to call early!***

There are also many teenagers with disabilities or chronic illness who do not receive special education services. These students do not have transition IEPs and so do not experience any formal transition planning. Even without formal planning, the best transitions will occur when a team works with the

youth and family to develop a systematic plan that supports the teen's goals. Young people with chronic conditions who have never received special education services may still qualify for assistance with job training, employment, and independent living through programs like Vocational Rehabilitation Services, FAAST, and Independent Living Centers (see resource listings).

The planning team should consider these items:

CHECK LIST

- ✓ **Self-determination** and self-advocacy skills
- ✓ **Vocational training** that won't conflict with health needs
- ✓ **Modifications** to physical education program
- ✓ **Classroom seating**, such as avoiding being next to windows because of allergies or noise
- ✓ **Health care management skills**, self-care, and knowledge of health insurance
- ✓ **Understanding own needs** and required accommodations
- ✓ **Special dietary needs**
- ✓ **Accessibility**, such as entrances, school activity areas, transportation, emergency evacuation
- ✓ **Stamina and strength issues**, such as carrying heavy books, scheduling classes
- ✓ **Medication**, medical supplies, and equipment
- ✓ **Volunteer experiences** and recreational activities to develop work and social skills

KNOW HOW TO IDENTIFY & ACCESS *COMMUNITY RESOURCES*

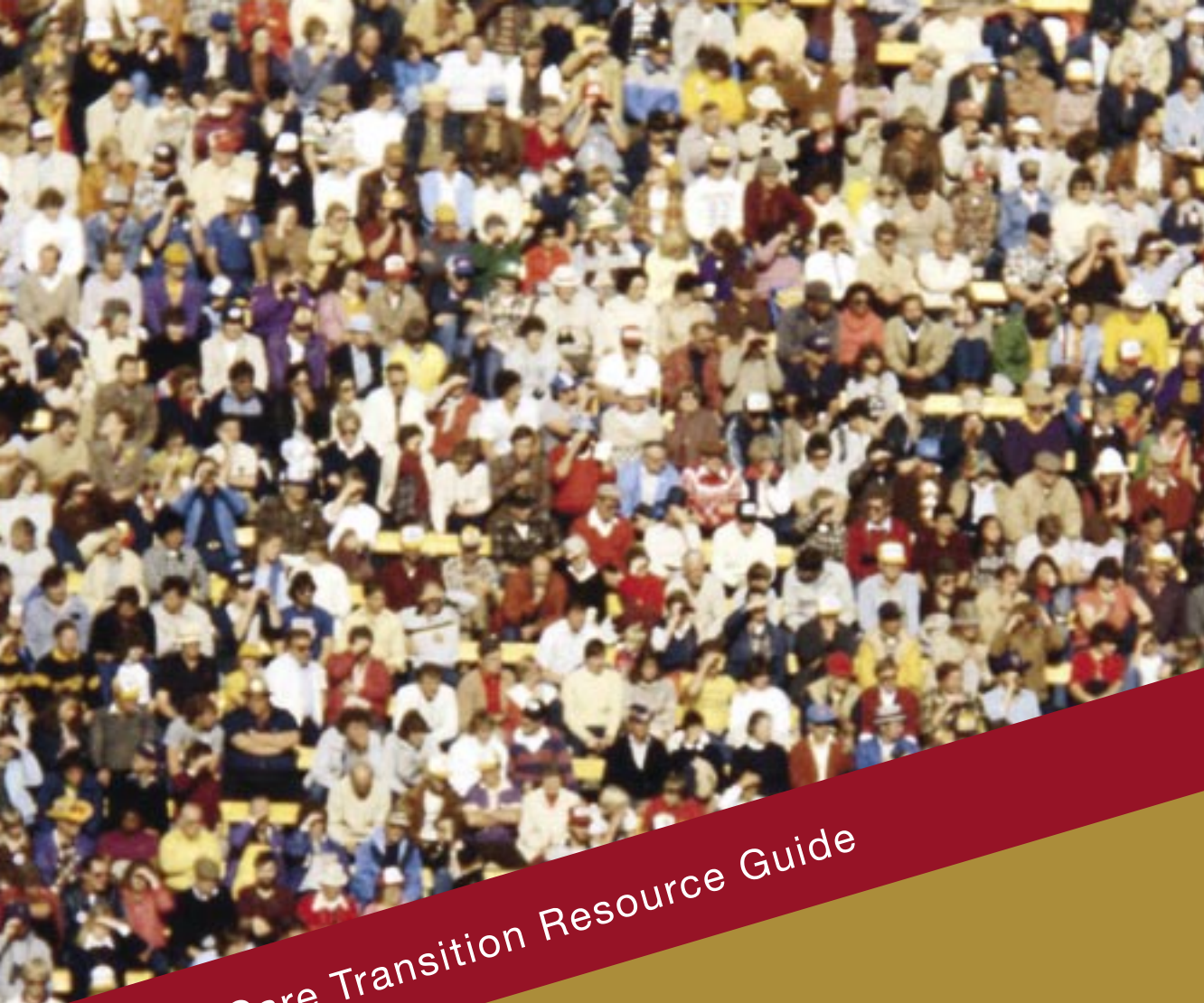
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Finally, it is important to know how to locate services that can help teens move from pediatric to adult health care. Although there is no legal requirement for agencies to provide health care transition services, there are resources that can help with the process.



In the enclosed guide are national, state, and local resources that might be useful. While the list does not include all resources that are available, it is a starting point for teens, families, and providers in planning for and locating adult health services.

This guide and updates to the listings will be posted online at <http://usfpeds.hsc.usf.edu/adolescent>. If you would like to submit a new or corrected listing, please call 813-259-8758.



Health Care Transition Resource Guide

RESOURCE



Florida Developmental Disabilities Council, Inc.

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For more information or to request additional copies of the guide, please contact the University of South Florida College of Medicine, Department of Pediatrics, at 813-259-8758. The guide may also be accessed online at <http://usfpeds.hsc.usf.edu/adolescent>.

