

A FAMILY TOOLKIT: PEDIATRIC-TO-ADULT HEALTH CARE TRANSITION

Developed by Got Transition[®] and its National Health Care Transition Family Advisory Group

ABOUT GOT TRANSITION[®]

Got Transition[®] is a program of The National Alliance to Advance Adolescent Health and is funded through a cooperative agreement from the federal Maternal and Child Health Bureau, Health Resources and Services Administration. Its aim is to improve transition from pediatric to adult health care through the use of innovative strategies for health care professionals and youth, families, and caregivers. For more health care transition resources and information about Got Transition, please visit <u>GotTransition.org</u>. For more information about The National Alliance to Advance Adolescent Health, please visit <u>TheNationalAlliance.org</u>.

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INTRODUCTION

Three major professional organizations – American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians – recommend that all youth receive pediatric-to-adult health care transition (HCT) services. Yet, national data consistently show that the majority of youth with and without special health care needs are not receiving needed HCT support from their health care providers.^{1,2} According to the 2017/2018 National Survey of Children's Health, 81% of youth with special health care needs and 86% of youth without special health care needs do not receive transition preparation services.² Youth and families report many barriers to transition, which include feeling unprepared to move to a new doctor and manage their own care, anxiety about leaving their current doctor, difficulty finding a new adult doctor, and understanding the adult health care system.¹

This toolkit was developed for families to use during pediatric-to-adult HCT and includes resources for both parents/caregivers and youth/young adults. The next page provides a summary of the tools that are included. These tools can be used to better prepare youth and families for the transition to adult care. This toolkit can be downloaded for free on Got Transition's website at <u>GotTransition.org</u>.

¹ White PH, Cooley WC, Transitions Clinical Authoring Group, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.

² Got Transition. *State, Region, and National Health Care Transition Performance for Youth With and Without Special Health Care Needs: The National Survey of Children's Health 2017-2018.* Washington, DC: Got Transition, 2018.

SUMMARY OF HEALTH CARE TRANSITION TOOLS

This toolkit has a set of resources for you to use as you work with your youth during the transition from pediatric to adult health care.

This toolkit includes two **<u>Health Care Transition (HCT) Timelines</u>** (pages 3-4), one for you and one for your youth. Each one has steps to take, starting at age 12, to prepare your youth to take charge of their own health and health care.

The **Parent Guide** (page 5) is a summary of clinical recommendations from three major professional organizations – American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians – on HCT for youth with and without special health care needs.

The **<u>Questions to Ask Your Doctor</u>** (pages 6-7) are questions for you and your youth to ask while getting ready to move to a new doctor and before making the first visit.

Changing Roles (page 8) shows how the roles of you and your youth change as your youth takes more control of their own health and health care. If you think you need legal decision-making support, the **Charting the Life Course** (page 9) tool – created by the University Center for Excellence in Developmental Disabilities at the University of Missouri-Kansas City Institute for Human Development – can be a useful tool for beginning the conversation with your youth about decision-making support needs in six areas: daily life and employment, healthy living, social and spirituality, safety and security, community living, and citizenship and advocacy.

The **Turning 18** tip sheet (page 11) shares some changes that happen when your youth turns 18 and is a legal adult. Two more tools show the differences between pediatric and adult care. The **Planning to Move from Pediatric to Adult Care** tool (page 12) is for youth. It shows how their care will change once they move to an adult approach to care, shares some thoughts from youth and young adults, and has tips to get ready for the change. **System Differences** (page 14) also has information about the major differences between pediatric and adult care.

To learn about your youth's knowledge about taking care of their own health, have them take the **Transition Readiness Assessment** on page 15. You can also take the readiness assessment on page 17 and compare your answers. Readiness assessments for youth with intellectual/ developmental disabilities and their parents/caregivers start on page 19. Your youth can also take an online **Health Care Transition Quiz** (page 23) that was created by Got Transition's National Youth and Young Adult Advisory Group as another test of how ready they are to transition to adult care.

For more resources, visit GotTransition.org or contact info@gottransition.org.



Health Care Transition Timeline

for Youth and Young Adults



parents/caregivers, visit https://gottransition.org/6ce/leaving-readiness-assessment-parent.

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Health Care Transition Timeline

for Parents/Caregivers



<u>https://gottransition.org/6ce/leaving-readiness-assessment-youth</u> and for a version for parents/ caregivers, visit <u>https://gottransition.org/6ce/leaving-readiness-assessment-parent</u>.

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PREPARING FOR THE TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE: PARENT GUIDE

Parents are familiar with the many transitions their children experience as they grow – their first steps, first words, first day of school, and last day of high school. But what about the last visit to the pediatrician or the first visit to an adult doctor? What about the planning that might make that transition less stressful and more successful? Many parents and youth do not consider this transition until it is suddenly upon them. And this may be even more true for youth and young adults with special health care needs who use the health care system more often.

The American Academy of Pediatrics (AAP), along with the American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) recently updated their recommendations for this important transition. In 2018 they published "<u>Supporting the Transition of Health Care from Adolescence to Adulthood in the Medical Home</u>." This clinical report offers guidance for pediatric and adult providers to help youth and parents gain skills to manage their own health as youth move to adult care.

The AAP advises that parents and their doctors begin to plan for transition as early as age 12. They also advise parents to plan for the move to an adult doctor between ages 14 and 18. Doctors and parents can assist their youth and young adults to manage their own health and health care. These skills include making an appointment and filling a prescription. It also includes knowing their personal and family health histories and asking questions during an office visit. During these years, transition planning could include asking the youth questions about their skills to manage their own health and making and sharing a medical summary and emergency care plan. The planning should include discussing changes in privacy and consent that happen at age 18 and preparing a plan of care with youth on their transition goals. The goal is to have this transition happen sometime between age 18 and the early 20s.

Health care transition may be different for youth and young adults with special needs. That includes those with serious chronic medical or behavioral needs and those with developmental or intellectual disabilities. These young adults may require more in-depth planning and on-going support because a variety of specialists can be involved. If the young adult will require help with health care decisions, legal plans for this must be in place by age 18.

Parents have a key role to play in helping their youth to learn to manage their health on their own. Below are a few questions that parents can ask their child's doctors:

- 1. When does my child start to meet with you alone for part of the visit to become more independent in their health care?
- 2. What does my child need to learn to get ready for adult health care? Do you have a checklist of self-care skills that my child needs to learn?
- 3. Can I work with you to prepare a medical summary and emergency care plan for my child?
- 4. Before my child turns 18, what information about privacy and consent do we need to learn about? If my child needs help making health decisions, where can I get information about this?
- 5. At what age does my child need to change to a new doctor for adults?
- 6. Do you know any adult doctors for my child to transfer to?

More information about transition to adult health care for youth, parents and guardians, and health care clinicians can be found at <u>GotTransition.org</u>.

The AAP, AAFP, and ACP would like all youth to be as ready and able as possible to manage their own health care needs and to navigate health care services throughout their lives. To build self-care skills, a structured process of planning achieved through a partnership between doctors, youth, and parents is key.





FOR YOUTH AND YOUNG ADULTS:

QUESTIONS TO ASK YOUR DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE*

DURING YOUR ADOLESCENT YEARS:

- □ When do I start to meet with you on my own for part of the visit to become more independent when it comes to my own health and health care?
- □ What do I need to learn to get ready for adult health care? Do you have a checklist of self-care skills that I need to learn?
- □ Can I work with you to prepare a medical summary for me and, if needed, a plan for what to do case of an emergency?
- □ When I turn 18, what information about privacy and consent do I need to know about? If I need help with making health decisions, where can I get information about this?
- □ At what age do I need to change to a new doctor for adult health care?
- □ Do you have any suggestions of adult doctors to transfer to?

BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:

- Do you take my health insurance? Do you require any payment at the time of the visit?
- □ Where is your office located? Is there parking or is it near a metro/bus stop?
- □ What are your office hours, and do you have walk-in times?
- □ What is your policy about making and cancelling appointments?
- □ How will I be able to communicate directly with the doctor after my visit or in the evenings?
- □ If needed, can the new adult doctor help me find adult specialty doctors?

BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:

- □ Did you receive my medical summary from my pediatric doctor? (Call your pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)
- \Box What should I bring to the first visit?
- □ Who can help me when you are not available?

NOTES:

*The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians recommend that all youth and young adults work with their doctor or other health care provider to build independence and prepare for the transition to adult care. For more information about transition, please visit gottransition.org/youth-and-young-adults and gottransition.org/parents-caregivers.





FOR PARENTS/CAREGIVERS:

QUESTIONS TO ASK YOUR CHILD'S DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE*

DURING YOUR CHILD'S ADOLESCENT YEARS:

- □ How do I best prepare my child to meet with you alone for part of their visit to become more independent when it comes to their own health and health care? When will they start to have time alone with you?
- □ What does my child need to learn to get ready for adult health care? Do you have a checklist of self-care skills that my child needs to learn?
- □ Can I work with you to prepare a medical summary for my child and, if needed, a plan for what to do in case of an emergency?
- □ Before my child turns 18 and becomes a legal adult, what information about privacy and consent do we need to learn about? If my child needs help with making health decisions, where can I get information about this?
- □ At what age does my child need to change to a new doctor for adult health care?

BEFORE TRANSFERRING TO A NEW ADULT DOCTOR:

- □ Do you have any suggestions of adult doctors for my child to transfer to?
- □ What kinds of doctors in adult care does my child need (e.g., a primary care doctor, a specialist, a behavioral health provider)?
- □ Will you send my child's medical summary to the new adult doctor?
- □ If needed, will you communicate with the new adult doctor about my child's care?
- □ Before the initial visit is made to the new adult doctor, will you still refill their medicines and treat them for acute care needs?

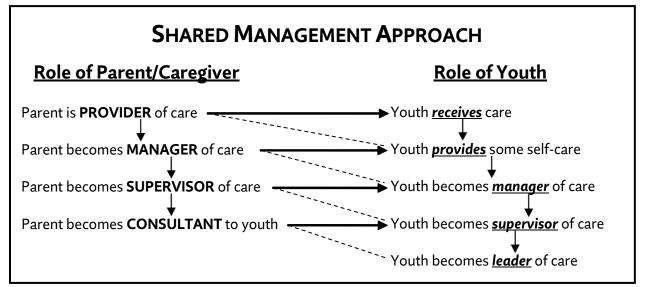
NOTES:

*The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians recommend that all youth and young adults work with their doctor or other health care provider to build independence and prepare for the transition to adult care. For more information about transition, please visit gottransition.org/youth-and-young-adults and gottransition.org/parents-caregivers.



WHAT ARE THE CHANGING ROLES OF PARENTS/CAREGIVERS AND YOUTH IN THE TRANSITION PROCESS?

The goal of pediatric-to-adult health care transition (HCT) is to improve the ability of youth and young adults to manage their own health and effectively use health services, and the role of parents/caregivers is to support this gradual movement from overseeing care for the youth to becoming a consultant (answering questions when asked) to the young adult around their health and health care. This is called a shared management approach and is shown below, displaying these changing roles. Each youth and parent/caregiver will travel through this process at their own pace. While moving through this process, it will be necessary to talk to your youth's doctor about necessary legal decision support documentation and other paperwork to support this approach.



Adapted from: University of WA Adolescent Health Transition Project. *Parent-Child Shared Management: Path to Independence.* Seattle, WA: 2010. Available at <u>https://depts.washington.edu/healthtr/documents/sharedmanage.pdf</u>.

Is your youth ready to become the <u>leader</u> of their care? Take Got Transition's transition readiness assessment to find out! For a youth version, visit <u>https://gottransition.org/6ce/leaving-readiness-assessment-youth</u>. For a parent/caregiver version, visit <u>https://gottransition.org/6ce/leaving-readiness-assessment-youth</u>. For a <u>assessment-parent</u>. For additional HCT information and resources, visit <u>GotTransition.org</u>.

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CHARTING the LifeCourse 🛃 📥



Tool for Exploring Decision Making Supports

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Friend

Family

Name of Individual: _

Name of person completing this form: ____

Relationship to individual (circle one): Self

How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.

I can decide with

Guardian

no extra support

Other:

I need support with my decision

I need someone to decide for me



DAILY LIFE & EMPLOYMENT

Can I decide if or where I want to work?	
Can I look for and find a job (read ads, apply, use personal contacts)?	
Do I plan what my day will look like?	
Do I decide if I want to learn something new and how to best go	
about that?	
Can I make big decisions about money? (<i>open bank account, make big purchases</i>)	
Do I make everyday purchases? (food, personal items, recreation)	
Do I pay my bills on time (rent, cell, electric, internet)	
Do I keep a budget so I know how much money I have to spend?	
Am I able to manage the eligibility benefits I receive?	
Do I make sure no one is taking my money or using it for themselves?	
HEALTHY LIVING	
Do I choose when to go to the doctor or dentist?	
Do I decide/direct what doctors, medical/health clinics, hospitals,	
specialists or other health care providers I use?	
Can I make health/medical choices for my day-to-day well-being?	
(check-ups, routine screening, working out, vitamins)	
Can I make medical choices in serious situations? (surgery, big injury)	
Can I make medical choices in an emergency?	
Can I take medications as directed or follow a prescribed diet?	
Do I know the reasons why I take my medication?	
Do I understand the consequences if I refuse medical treatment?	
Can I alert others and seek medical help for serious health problems?	
Do I make choices about birth control or pregnancy?	
Do I make choices about drugs or alcohol?	
Do I understand health consequences associated with choosing high	
risk behaviors (substance abuse, overeating, high-risk sexual	
activities, etc.)?	
Do I decide where, when, and what to eat?	
Do I understand the need for personal hygiene and dental care?	

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For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.

I can decide with no extra support

.....

I need support with my decision I need someone

to decide for me

SOCIAL & SPIRITUALITY

Do I choose where and when (and if) I want to practice my faith?	
Do I make choices about what to do and who to spend time with?	
Do I decide if I want to date, and choose who I want to date?	
Can I make decisions about marriage (If I want to marry, and who)?	
Can I make choices about sex, and do I understand consent and	
permission in regard to sexual relationships?	
SAFETY & SECURITY	
Do I make choices that help me avoid common environmental	
dangers (traffic, sharp objects, hot stove, poisonous products, etc.)?	
Do I make plans in case of emergencies?	
Do I know and understand my rights?	
Do I recognize and get help if I am being treated badly (physically,	
emotionally or sexually abused, or neglected)	
Do I know who to contact if I feel like I'm in danger, being exploited,	
or being treated unfairly (police, attorney, trusted friend)?	
COMMUNITY LIVING	
Do I decide where I live and who I live with?	
Do I make safe choices around my home (turning off stove, having	
fire alarms, locking doors)?	
Do I decide about how I keep my home or room clean and livable?	
Do I make choices about going places I travel to often (work, bank,	
stores, church, friends' home)?	
Do I make choices about going places I don't travel to often (<i>doctor</i>	
appointments, special events)?	
Do I decide how to get to the places I want or need to go? (walk, ask	
a friend for a ride, bus, cab, car service)	
Do I decide and direct what kinds of support I need or want and	
choose who provides those supports?	
CITIZENSHIP & ADVOCACY	
Do I decide who I want to represent my interests and support me?	
Do I choose whether to vote and who I vote for?	
Do I understand consequences of making decisions that will result in	
me committing a crime?	
Do I tell people what I want and don't want (verbally, by sign,	
device), and tell people how I make choices?	
Do I agree to and sign contracts and other formal agreements, such	
as powers of attorney?	
Do I decide who I want information shared with (family, friends etc.)?	
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Turning 18: What it Means for Your Health

Turning 18 may not make you feel any different, but legally, this means you are an adult.

What does this mean?

- After you turn 18, your doctor talks to **you**, not your parents, about your health.
- Your health information and medical records are private (or confidential) and can't be shared unless you give the OK.
- It is up to you to make decisions for your own health care, although you can always ask others for help.

Things to know

- The confidentiality between you and your doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA.
- This law gives privacy rights to minors (people who are under age 18) for reproductive and sexual health, mental health, and substance abuse services. Check your state's minor consent laws for more information.

What needs to be done?

- If you want to share medical information with others, your doctor will ask you to fill out a form that allows them to see your medical record and be with you during your visit.
- If you need help making decisions, talk to your family, your support team, and your doctor about who needs to be involved and what you need to do to make sure they can be a part of the conversations.

Additional resources

• If you want extra support managing your health or making decisions, the <u>National</u> <u>Resource Center for Supported Decision-Making</u> has information to connect you with resources in your state.

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PLANNING TO MOVE FROM PEDIATRIC TO ADULT CARE? HERE'S HOW THEY CAN DIFFER

Health care for youth is different than health care for adults. In adult care, you are in charge of your own care and involve your parents/caregivers if you choose. These are some of the changes that happen when you move to adult care.

Please circle any items in the Adult Approach to Care column that you have questions about. Bring this to your next doctor visit to start a conversation about any questions you may have.

Pediatric Care (Where you are now)	Adult Approach to Care (Where you will be)
Your parent/caregiver is with you for most or all of your visit.	You see the doctor alone unless you agree for others to be present.
Your parent/caregiver helps answer questions and explain your medical conditions, any medicines, and medical history.	You answer questions and explain your medical conditions, medicines, and medical history.
Your parent/caregiver is involved in making choices about your care.	You make your own choices about your care, asking your parents/ caregivers as needed.
Your parent/caregiver helps make appointments and get your medicines.	You make your own appointments and get your medicines.
Your parent/caregiver helps with your care and reminds you to take your medicines.	You take control of your care and take medicines on your own.
Your parent/caregiver can see your health information, including test results.	Health information is private unless you agree to let others see it.
Your parent/caregiver knows your health insurance and pays any charges at the visit.	You keep your health insurance card with you and pay any charges at the visit.
Your parent/caregiver keeps a record of your medical history and vaccines.	You keep a record of your medical history and vaccines.
Many pediatric specialists provide both specialty and some primary care.	Adult specialists often do not provide primary care, so you need to have a primary care doctor along with a specialist.

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YOUTH AND YOUNG ADULT THOUGHTS ON MOVING TO ADULT CARE



"The fact that I will have to go ... and not being familiar with it. That's probably where the nervousness comes in."

"I guess that's one of the reasons I'm not jumping to change doctors is because I feel close to him and I trust him."

From youth in pediatric care¹

From young adults in adult care¹

"They treat you more maturely. They expect you to know your responsibilities and stuff ... I like it. I like to have responsibility. I mean it's knowing ... you have to know your medications and everything." "She gave me this big talk about some of the new things I'm going to encounter as an adult with a chronic condition. And she just opened my eyes to a lot of things."

TIPS FOR PREPARING FOR YOUR MOVE TO ADULT HEALTH CARE

- Write down a list of questions and concerns you have before seeing your new doctor.
- Keep a list of your medicines, how much you take, and any allergies to medicines. You can take a picture of your medicines label and bring it with you to your visit.
- Keep your doctor's phone number in your phone or somewhere you can easily find it.
- Keep your health insurance card with you always.
- Keep a record of your medical history, allergies and vaccines to share with your new doctor.
- Ask your doctor where to go if you need to get care after office hours or on the weekend.
- Ask your doctor to explain information you do not understand
- Ask your doctor if there is an online portal or an app you can use to look up your health information, contact information, or to make appointments.

TEST HOW READY YOU ARE TO MOVE TO ADULT CARE BY TAKING THIS QUIZ: https://www.gottransition.org/youth-and-young adults/HCT-quiz.cfm

¹Tuchman LK, Slap GB, and Britto MT. Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development.* 2008;34(5):557-63.

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System Characteristics	Pediatric	Adult
Orientation to Care	Growth and development	Maintenance of well-being with aging
Practice Approach	Family-centered; shared decision- making with parents	Patient-centered; shared decision- making with young adult
Primary Care Practice Patient Population	Majority of patients do not have chronic conditions	Majority of patients have chronic conditions
Specialty Clinic Affiliation/Location	Most pediatric specialty clinics located in children's hospitals	Most adult specialty practices located in private office-based settings
Multidisciplinary Staffing	Most pediatric specialty clinics are co- located with other specialists and can offer ancillary therapies	Most adult specialty clinics are not co-located with other specialists and need to refer out to other specialists and ancillary therapists
Availability of Care Coordination	Most pediatric subspecialty clinics and many pediatric primary care practices have care coordination services. Several public care coordination programs (e.g., State Title V program) are available for youth with specific chronic conditions	Few adult specialty clinics and even fewer adult primary care practices have the availability of care coordination services. Few public care coordination programs are available for adults with chronic conditions
Length of Appointment	Longer time	Shorter time
Time Alone	Sometimes for part of visit	Legally required for confidentiality over age 18, unless young adult gives permission for others to be present
Patient Role as Self Advocate	Less, given parental support/ presence during visit	Essential
Patient Role in Making Appointments and Medication Refills	Parent handles	Patient handles
Adherence to Care	Offer more reminders and work arounds (e.g., using shots or intravenous medications); provider has legal option of contacting protective services if needed	Expectation of adherence; up to patient to follow treatment/ medication recommendations; provider has no legal options
Medication Dosage	Depends on weight	Commonly one adult dose, but occasionally related to weight
Use of Pain Medications	More liberal availability	More restrictive availability
Time in Care System	Usually about 20-25 years	Average 50+ years

SYSTEM DIFFERENCES BETWEEN PEDIATRIC AND ADULT HEALTH CARE

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Sample Transition Readiness Assessment for Youth

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name	name Legal name Date of				te of birth	Today	ı's date	
TRANSITION IMPORTA	NCE & CONFI	DENCE P	lease circle t	he number t	that <u>best</u> des	scribes how you	feel now.	
The transfer to adult heal	-	-		-		22.		
How important is it to you to			1	1	-		_	
0 1 2	3	4	5	6	7	8	9	10 <i>_ very</i>
How confident do you feel	about vour abilit	v to move	to a doctor	who cares	for adults b	before age 22	?	
0 1 2	3	4	5	6	7	8	9	10
not								_ very
MY HEALTH & HEALTH	CARE Please cl	neck the ansi	ver that <u>best</u>	applies now		NO	I WANT TO LEARN	YES
I can explain my health ne	eeds to others.							
I know how to ask questio	ons when I do no	t understa	nd what my	doctor say	/S.			
I know my allergies to me	dicines.							
I know my family medical	history.							
I talk to the doctor instead	l of my parent/ca	aregiver tal	king for me					
I see the doctor on my ow	n during an app	ointment.						
I know when and how to g	, ,							
I know where to get medic								
I carry important health int emergency contact inform	formation with m nation).	ne every da	ay (e.g., ins	urance car	d,			
I know that when I turn 18	8, I have full priva	acy in my h	ealth care.					
I know at least one other p	person who will	support me	e with my he	ealth needs	3.			
I know how to find my doo	ctor's phone num	nber.						
I know how to make and c	cancel my own d	octor appo	intments.					
I have a way to get to my	doctor's office.							
I know how to get a summ	nary of my medio	cal informa	tion (e.g., o	online porta	l).			
I know how to fill out medi								
I know how to get a referra	al if I need it.							
I know what health insura								
I know what I need to do t								
I talk with my parent/careg	giver about the h	ealth care	transition p	process.				
MY MEDICINES If you do	o not take any med	licines, plea	se skip this s	ection.				
I know my own medicines								
I know when I need to tak	-			ng me.				
I know how to refill my me	edicines if and w	hen I need	to.					

WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?



Transitioning Youth to an Adult Health Care Clinician Six Core Elements of Health Care Transition[™] 3.0



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How to Score the Transition Readiness Assessment for Youth (For Office Use Only)

The purpose of the transition readiness assessment is to begin a discussion with youth about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes.

This scoring sheet can be filled out to score a youth's completed transition readiness assessment or it can be used as a scoring guide to refer to when marking the score on their completed assessment.

Each response can be converted to a score of 0 (No), 1 (I want to learn), or 2 (Yes). Because not all youth are taking medicines, numbers in "My Health & Health Care" and "My Medicines" should be calculated separately.

MY HEALTH & HEALTH CARE Please check the answer that <u>best</u> applies now.	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	0	1	2
I know how to ask questions when I do not understand what my doctor says.	0	1	2
I know my allergies to medicines.	0	1	2
I know my family medical history.	0	1	2
I talk to the doctor instead of my parent/caregiver talking for me.	0	1	2
I see the doctor on my own during an appointment.	0	1	2
I know when and how to get emergency care.	0	1	2
I know where to get medical care when the doctor's office is closed.	0	1	2
I carry important health information with me every day (e.g., insurance card, emergency contact information).	0	1	2
I know that when I turn 18, I have full privacy in my health care.	0	1	2
I know at least one other person who will support me with my health needs.	0	1	2
I know how to find my doctor's phone number.	0	1	2
I know how to make and cancel my own doctor appointments.	0	1	2
I have a way to get to my doctor's office.	0	1	2
I know how to get a summary of my medical information (e.g., online portal).	0	1	2
I know how to fill out medical forms.	0	1	2
I know how to get a referral if I need it.	0	1	2
I know what health insurance I have.	0	1	2
I know what I need to do to keep my health insurance.	0	1	2
I talk with my parent/caregiver about the health care transition process.	0	1	2
MY MEDICINES If you do not take any medicines, please skip this section.			
I know my own medicines.	0	1	2
I know when I need to take my medicines without someone telling me.	0	1	2
I know how to refill my medicines if and when I need to.	0	1	2

My Health & Health Care Total Score: _____/40

My Medicines Total Score: _____ / 6



Transitioning Youth to an Adult Health Care Clinician Six Core Elements of Health Care Transition[™] 3.0

Sample Transition Readiness Assessment for Parents/Caregivers

Please fill out this form to help us see what your child already knows about their health and the areas you think they want to learn more about. After you complete the form, you can ask your child to share their answers from their completed form, and you can compare them. Your answers may be different. Your child's doctor will help you work on steps to increase your child's health care skills.

Youth name Parent/Caregiver name Yo	outh date of bir	rth Toda	y's date
TRANSITION IMPORTANCE & CONFIDENCE Please circle the number that best de	escribes how y	ou feel now.	
The transfer to adult health care usually takes place between the ages of 18 an	d 22.		
How important is it to your child to move to a doctor who cares for adults before age			1
0 not 1 2 3 4 5 6 7	8	9	10 very
How confident do you feel about your child's ability to move to a doctor who cares for	r adults befor	e age 222	0
0 1 2 3 4 5 6 7	8	9	10
not		1	very
MY CHILD'S HEALTH & HEALTH CARE Please check the answer that best applies now). N	O THEY WA TO LEAR	NT YES
My child can explain their health needs to others.			
My child knows how to ask questions when they do not understand what their doctor sa	ys. 🗆		
My child knows their allergies to medicines.			
My child knows our family medical history.			
My child talks to the doctor instead of me talking for them.			
My child sees the doctor on their own during an appointment.			
My child knows when and how to get emergency care.			
My child knows where to get medical care when the doctor's office is closed.			
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	C		
My child knows that when they turn 18, they have full privacy in their health care.			
My child knows at least one other person who will support them with their health need	ls. 🗆		
My child knows how to find their doctor's phone number.			
My child knows how to make and cancel their own doctor appointments.			
My child has a way to get to their doctor's office.			
My child knows how to get a summary of their medical information (e.g., online porta	al). 🗆		
My child knows how to fill out medical forms.			
My child knows how to get a referral if they need it.			
My child knows what health insurance they have.			
My child knows what they need to do to keep their health insurance.			
My child and I talk about the health care transition process.			
MY CHILD'S MEDICINES If your child does not take any medicines, please skip this section	on.		
My child knows their own medicines.			
My child knows when they need to take their medicines without someone telling the	m . 🗆		
My child knows how to refill their medicines if and when they need to.	C		

WHICH OF THE SKILLS LISTED ABOVE DOES YOUR CHILD MOST WANT TO WORK ON?



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How to Score the Transition Readiness Assessment for Parents/Caregivers (For Office Use Only)

The purpose of the transition readiness assessment is to begin a discussion with youth and parents/caregivers about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes.

This scoring sheet can be filled out to score a parent/caregiver's completed transition readiness assessment or it can be used as a scoring guide to refer to when marking the score on their completed assessment.

Each response can be converted to a score of 0 (No), 1 (They want to learn), or 2 (Yes). Because not all youth are taking medicines, numbers in "My Child's Health & Health Care" and "My Child's Medicines" should be calculated separately.

MY CHILD'S HEALTH & HEALTH CARE Please check the answer that best applies now.	NO	THEY WANT TO LEARN	YES
My child can explain their health needs to others.	0	1	2
My child knows how to ask questions when they do not understand what their doctor says.	0	1	2
My child knows their allergies to medicines.	0	1	2
My child knows our family medical history.	0	1	2
My child talks to the doctor instead of me talking for them.	0	1	2
My child sees the doctor on their own during an appointment.	0	1	2
My child knows when and how to get emergency care.	0	1	2
My child knows where to get medical care when the doctor's office is closed.	0	1	2
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	0	1	2
My child knows that when they turn 18, they have full privacy in their health care.	0	1	2
My child knows at least one other person who will support them with their health needs.	0	1	2
My child knows how to find their doctor's phone number.	0	1	2
My child knows how to make and cancel their own doctor appointments.	0	1	2
My child has a way to get to their doctor's office.	0	1	2
My child knows how to get a summary of their medical information (e.g., online portal).	0	1	2
My child knows how to fill out medical forms.	0	1	2
My child knows how to get a referral if they need it.	0	1	2
My child knows what health insurance they have.	0	1	2
My child knows what they need to do to keep their health insurance.	0	1	2
My child and I talk about the health care transition process.	0	1	2
MY CHILD'S MEDICINES If your child does not take any medicines, please skip this section.			
My child knows their own medicines.	0	1	2
My child knows when they need to take their medicines without someone telling them.	0	1	2
My child knows how to refill their medicines if and when they need to.	0	1	2

My Child's Health & Health Care Total Score: _____ /40

My Child's Medicines Total Score: _____ / 6



Transitioning Youth to an Adult Health Care Clinician Six Core Elements of Health Care Transition[™] 3.0

Pediatric to Adult Care
Transitions ToolsTransition Readiness Assessment for Youth with
Intellectual/Developmental Disabilities

This document should be completed by youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their readiness to transition to an adult heath care provider. If a youth's intellectual or developmental disabilities prevent him or her from independently filling out this document, the youth's caregiver should fill out the caregiver version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what you already know about your health and using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Date:

Name:

Date of Birth:

Legal Choices for Making Health Care Decisions

[I can make my own health care choices.
		I need some help with making health care choices (Name: Consent:).
		I have a legal guardian (Name:).
		I need a referral to community services for legal help with health care decisions and guardianship.
Pers	on	al Care
[I care for my all my needs.
[I care for my own needs with help.
		I am unable to provide self-care, but can direct others.

I require total personal care assistance.

Transition and Self-Care Importance and Confidence On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to take care of your own health care and change to adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
How confident do you feel about your ability to take care of your own health care and change to an adult doctor before age 22?										
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health	Please check the box that applies to you right now.	Yes, I know this.	l need to learn.	Someone needs to do this Who?
I know my medical needs.				
I can tell other people wha	t my medical needs are.			
I know what to do if I have	a medical emergency.			
	e and what they are for, and when I need to take them without			_
someone reminding me.				
I know what medicines I sh	ould not take.			
I know what I am allergic to	o, including medicines.			
I can name 2-3 people who	o can help with my health goals.			
I can explain to people how	v my beliefs affect my care choices.			
Using Health Care	Please check the box that applies to you right now.	Yes, I know this.	I need to learn.	Someone needs to do this Who?
I know or I can find my doo	tor's phone number.			
I make my own doctor app	ointments.			
Before a visit, I think about	questions to ask.			
I have a way to get to my o	loctor's office.			
I know I should show up 1	5 minutes before the visit to check in.			
I know where to get care w	hen my doctor's office is closed.			

Transitions Tools

Pediatric to Adult Care Transition Readiness Assessment for Youth with Intellectual/Developmental Disabilities

Using Health Care	Please check the box that applies to you right now.	Yes, I know this.	l need to learn.	Someone needs to do this Who?
I have a folder at home with my medical information, including my medical summary and emergency care plan.				
I have a copy of my plan of care.				
I know how to fill out medical forms.				
I know how to ask for a form to be seen by other doctors or therapist.				
I know where my pharmacy is and what to do when I run out of my medicines.				
I know where to get a blood test or x-rays if the doctor orders them.				
I carry my health information with me every day (e.g. insurance card, allergies, medications, and emergency phone numbers).				
I have a plan so I can keep m	rules about my health privacy change. Iy health insurance after 18 or older.			
(If applies) I have a plan so I	can keep my disability benefits (SSI) after 18.			

Pediatric to Adult Care Transitions Tools

0 (not)

1

2

3

4

Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual/Developmental Disabilities

This document should be completed by caregivers of youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their youth's readiness to transition to an adult heath care provider. If a youth's intellectual or developmental disabilities do not prevent him or her from independently filling out this document, the youth should fill out the youth version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what your youth already knows about their health and using health care and areas that you think they/you need to learn more about. If you need help completing this form, please let us know.

Date:	
Patient Name:	Date of Birth:
Caregiver Name:	Are you the main/full-time caregiver? \Box Yes \Box No
Decision-making/Guardianship	
My youth can make my own health care choices.	
My youth needs some help with making health care choic	s (Name: Consent:).
My youth has a legal guardian (Name:).
My youth/l need a referral to community services for legal	elp with health care decisions and guardianship.
Personal Care	
My youth can care for all his/her needs.	
□ My youth can care for his/her own needs with help.	
□ My youth is unable to care for himself/herself, but can tell	others his/her needs.
My youth requires help for all his/her needs.	
Transition Importance and Confidence On a scale of 0 to	10, please circle the number that best describes how you feel right now.
How important is for your youth to prepare for and change to an adu	doctor before age 22?
0 (not) 1 2 3 4 5	6 7 8 9 10 (very)
How confident do you feel about your youth's ability to prepare for a	d change to an adult doctor before 22?

Your Youth's Health	Please check the box that applies to you right now.	Yes, my youth knows this.	My youth needs do learn this.	I need to learn this.
My youth knows his/her medical ne	eeds.			
My youth can tell other people what his/her medical needs are.				
My youth knows what to do if he/she has a medical emergency.				
My youth knows the medicines he/she takes and what they are for.				
My youth can take his/her medicine by himself/herself without a reminder.				
My youth knows what medicines he/she should not take.				
My youth knows what he/she is allergic to, including medicines.				
My youth can name 2-3 people wh	o can help him/her with his/her health goals			
My teen can explain to people how	/ his/her beliefs affect his/her care choices.			

5

6

7

8

9

10 (very)

Transitions Tools

Pediatric to Adult Care Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual/Developmental Disabilities

Using Health Care Please check the box that applies to you right now.	Yes, my youth knows this.	My youth needs to learn this.	I need to learn this.
My youth knows or can find his/her doctor's phone number.			
My youth makes his/her own doctor appointments.			
Before a visit, my youth thinks about questions to ask.			
My youth has a way to get to his/her doctor's office.			
My youth knows he/she should show up 15 minutes before the visit to check in.			
My youth knows where to get care when his/her doctor's office is closed.			
My youth has a folder at home with his/her medical information, including his/her medical summary and emergency care plan.			
My youth has a copy of his/her plan of care.			
My youth knows how to fill out medical forms.			
My youth knows how to ask for a form to be seen by other doctors or therapists.			
My youth knows where his/her pharmacy is and what to do when he/she runs out of his/her medicines.			
My youth knows where to get a blood test or x-rays if the doctor orders them.			
My youth carries health information with him/her every day (e.g. insurance card, allergies, medications, and emergency phone numbers).			
My youth knows when he/she is 18 the rules about his/her health privacy change.			
My youth has a plan so he/she can keep his/her health insurance after 18 or older.			



Are you ready to transition to adult health care? Take the quiz here:

https://gottransition.org/youth-andyoung-adults/hct-quiz.cfm



