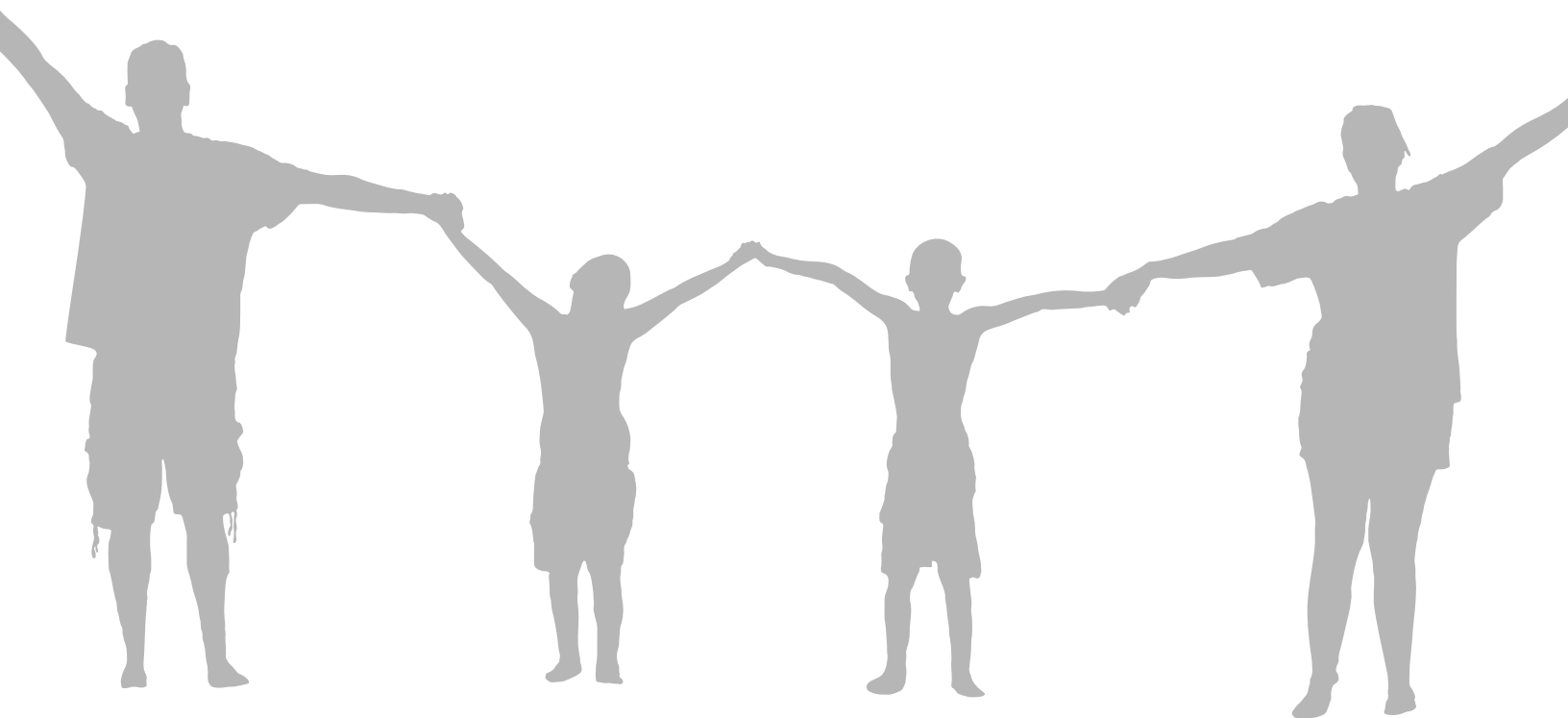

TRANSITION TO ADULT HEALTH CARE

HANDBOOK FOR YOUTH AND YOUNG ADULTS



CHILD HEALTH SPECIALTY CLINICS
DIVISION OF CHILD AND COMMUNITY HEALTH
UNIVERSITY OF IOWA

TABLE OF CONTENTS

Purpose of this Handbook

Introduction to the Transition to Adult Health Care

Transition Timelines

- Questions to Ask Your Child's Doctor About Transitioning to Adult Health Care: Guide for Parents and Caregivers
- Questions to Ask Your Doctor About Transitioning to Adult Health Care: Guide for Youth and Young Adults
- Sample Transition Readiness Assessment for Youth
- Sample Transition Readiness Assessment for Parents/Caregivers
- Sample Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual/Developmental Disabilities
- Differences in Care Between Pediatric and Adult Care

Health Needs, Medications, and Allergies

- Sample Medical Summary and Emergency Care Plan

Health Record Privacy

- Turning 18: What It Means For Your Health

Planning for a Health Emergency

Understanding Health Care Forms

Making Healthy Choices

Medical Appointments and Communication

- Tips for Finding and Using Adult Health Care
- Role Play Example: Paperwork at Sign-In Desk
- Role Play Example: Scheduling an Appointment

Transportation to Medical Appointments

Medications and Medication Refills

- Role Play Example: Calling in a Prescription
 - Understanding Your Prescription Label
 - Filling a Prescription Resource
 - Taking Medications as Directed
-

TABLE OF CONTENTS CONTINUED

Understanding Health Insurance

- Health Insurance 101

Finding Adult Health Care Providers

- Making the Most of Your Visit with Your Provider

Making Decisions After Age 18

- Guardianship and Decision-Making Handout

Social Services for Adults

Additional Resources

- Activities of Daily Living Assessment
-

PURPOSE OF THIS HANDBOOK

This Transition to Adult Health Care Handbook serves two purposes:

- To assist parents and caregivers of children and youth with special health care needs in understanding how to support their youth as they transition to adult health care
- To assist youth and young adults with special health care needs in understanding their role and what supports are in place as they transition to adult health care

This handbook is not meant to be an exhaustive list of how to transition youth with special health care needs to the adult health care system. Instead, it is intended to be used as a guide for how to approach the transition to adult health care for youth with special health care needs for the following audiences:

- Parents/caregivers
- Parents/caregivers of youth with additional needs
- Youth/young adults

There are many reputable organizations that provide excellent resources on the transition to adult health care. The Transition to Adult Health Care Handbook will provide direction to these external resources to help you or your youth in their transition.

Disclaimer: *This handbook contains legal and financial information and resources but does not contain legal or financial advice.*

INTRODUCTION TO THE TRANSITION TO ADULT HEALTH CARE

YOUTH & YOUNG ADULTS

What is Health Care Transition?

Health Care Transition is the process of getting ready for health care as an adult.

During childhood, your parents or caregivers usually help you with your health needs. This might look like:

- Calling the provider's office to schedule your appointments
- Filling out your medical forms at the provider's office
- Making sure that you take your medications
- Advocating for you in health care settings

As you get older, you might need to become more responsible for managing your health. This might look like:

- Gaining independent health skills
- Preparing to navigate the adult health care system
- Finding adult health care providers that fit your needs

As you turn 18 years old, you may need to become more responsible for your health. You may also find ways for your parents or caregivers to assist you as you head into adulthood. There will be resources in this handbook that will help you and your caregivers navigate these changes.

Remember: *You are not alone in this process! There are health care providers and community supports to assist you with this transition.*

TRANSITION TIMELINE

FOR YOUTH & YOUNG ADULTS

Age 12-13

- Learn about your health condition, medications, and allergies
- Start asking your provider questions about your health
- Ask your doctor if, and at what age, they no longer care for young adults

Age 14-15

- Find out what you know about your health, health care, and medical history
- Carry your own health insurance card
- Learn what to do in case of a health emergency
- Practice making appointments and ordering prescription refills
- Begin to see your provider alone for part of the visit to learn skills in managing your health and health care

Age 16-17

- Make appointments, see your provider alone, ask your provider questions, and start refilling your own medications
- Learn about your privacy rights when you turn 18
- Make a medical summary with your doctor and keep a copy for yourself
- Before you turn 18, figure out if you will need help making health care decisions and explore those options with your parents/caregivers

Age 18-21

- You are a legal adult at age 18 and are now responsible for your health (unless substitute decision-making arrangements were made)
- Your parents/caregivers cannot have access to your medical records unless you allow them
- If needed, work with your current provider to find a new adult provider that accepts your health insurance
- Call your new adult provider to schedule your first appointment and transfer your medical records
- Learn about any changes that might affect you when you turn 18 such as: health insurance changes, Social Security Income, etc.

Age 22-25

- Continue to receive care from your adult provider, manage your health and health care, and update your medical summary
- Be sure to stay insured and update your provider if there are any changes in your health insurance coverage



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.)
- 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.

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 _____ Legal name _____ Date of birth _____ Today's date _____

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to you to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not _____ very

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*

	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to ask questions when I do not understand what my doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk to the doctor instead of my parent/caregiver talking for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I see the doctor on my own during an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know that when I turn 18, I have full privacy in my health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know at least one other person who will support me with my health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to make and cancel my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a summary of my medical information (e.g., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a referral if I need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what health insurance I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I need to do to keep my health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talk with my parent/caregiver about the health care transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MY MEDICINES *If you do not take any medicines, please skip this section.*

I know my own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when I need to take my medicines without someone telling me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to refill my medicines if and when I need to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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 <i>Please check the answer that best applies now.</i>	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 <i>If you do not take any medicines, please skip this section.</i>			
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



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 <i>Please check the answer that best applies now.</i>	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 <i>If your child does not take any medicines, please skip this section.</i>			
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

Pediatric to Adult Care Transitions Tools

Transition 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 health 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.

Personal 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	<i>Please check the box that applies to you right now.</i>	Yes, I know this.	I need to learn.	Someone needs to do this... Who?
I know my medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can tell other people what my medical needs are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do if I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the medicines I take and what they are for, and when I need to take them without someone reminding me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what medicines I should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I am allergic to, including medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can name 2-3 people who can help with my health goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain to people how my beliefs affect my care choices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using Health Care	<i>Please check the box that applies to you right now.</i>	Yes, I know this.	I need to learn.	Someone needs to do this... Who?
I know or I can find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I make my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, I think about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know I should show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get care when my doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Pediatric to Adult Care
Transitions Tools**

**Transition Readiness Assessment for Youth with
Intellectual/Developmental Disabilities**

Using Health Care	<i>Please check the box that applies to you right now.</i>	Yes, I know this.	I 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.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a copy of my plan of care.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to ask for a form to be seen by other doctors or therapist.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where my pharmacy is and what to do when I run out of my medicines.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get a blood test or x-rays if the doctor orders them.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry my health information with me every day (e.g. insurance card, allergies, medications, and emergency phone numbers).		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know that when I am 18 the rules about my health privacy change.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a plan so I can keep my health insurance after 18 or older.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(If applies) I have a plan so I can keep my disability benefits (SSI) after 18.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

DIFFERENCES IN CARE BETWEEN PEDIATRIC AND ADULT CARE

GUIDE FOR YOUTH AND FAMILIES

Services		
Pediatric	Adult	Helpful Tips
<ul style="list-style-type: none"> You might be seen by a team of providers at the same visit You might have a number of support services to help you Your providers focus on your present and future possibilities Your parent/caregiver is told about your health information and medical care 	<ul style="list-style-type: none"> You might need to see providers at different locations and on different days You might not qualify for the services you received before you turned 18 Your adult providers might focus on what you can do in the present Your health information will be kept private and can only be shared with your consent If you have a guardian, they will be told about your health information 	<ul style="list-style-type: none"> Find an adult primary care provider who will help you coordinate care with specialists and other providers Talk to a social worker about adult services you may need and be eligible for (personal assistant, home services, financial help, etc.) Ask your provider to help you think about how work choices may affect your health and explore available accommodations Be sure to sign a consent to share your health information with whom you choose

Insurance and Payment		
Pediatric	Adult	Helpful Tips
<ul style="list-style-type: none"> Parents/caregivers help you with your insurance benefits (referral process, co-pays, in-network providers) Parents/caregivers pay for your medical care You may have insurance coverage available only to dependents (parent/caregiver's policy) or children through age 18 	<ul style="list-style-type: none"> You will be more responsible for knowing and using your adult insurance benefits You will need to pay for your own medical care You may need to find new insurance to cover you as an adult (employer benefits, Health Benefits for Workers with Disabilities, etc.) 	<ul style="list-style-type: none"> Learn ways to maximize your benefits Learn about adult insurance options Find out when your current coverage will end

Information adapted from handout by UIC – Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics

HEALTH NEEDS, MEDICINES, AND ALLERGIES

YOUTH & YOUNG ADULTS

Your teen years are a great time to learn more about your health issue, how to manage it, and practice taking medication on your own.

You can begin understanding your health needs by:

- Learning about your health issues
- Understanding when to take your medications
- Learning how to make your own appointments

Helpful Tips

- Think about what you know right now about your health issue, medications, or allergies
- Learn more about your health issue by researching it using websites like MedlinePlus. Discuss what you learned with your health care provider
- Before appointments, think of at least one question to ask your provider
- Use a pillbox or other system to keep track of when you take medications
- Use a calendar to keep track of appointments and medication refills
- Keep a copy of your insurance card with you. If you don't have a copy of your insurance card, ask your parent or caregiver for one.

Assess Your Transition Readiness

Got Transition is the federally funded national resource center on health care transition. It aims to improve transition from pediatric to adult health care using evidence-driven strategies for health care professionals, youth, young adults, and their families.

Got Transition has developed a "Health Care Transition Quiz". Take this quiz to see if you are ready to start the transition to adult health care. If applicable, share your results with your parents or caregivers.

Health Care Transition Quiz for Youth & Young Adults:

<https://gottransition.org/youth-and-young-adults/hct-quiz.cfm>



Sample Medical Summary and Emergency Care Plan

Six Core Elements of Health Care Transition 2.0

This document should be shared with and carried by youth and families/caregivers.

Date Completed: _____ Date Revised: _____

Form completed by: _____

Contact Information

Name: _____ Nickname: _____

DOB: _____ Preferred Language: _____

Parent (Caregiver): _____ Relationship: _____

Address: _____

Cell #: _____ Home #: _____ Best Time to Reach: _____

E-Mail: _____ Best Way to Reach: Text Phone Email

Health Insurance/Plan: _____ Group and ID #: _____

Emergency Care Plan

Emergency Contact: _____ Relationship: _____ Phone: _____

Preferred Emergency Care Location: _____

Common Emergent Presenting Problems	Suggested Tests	Treatment Considerations

Special Concerns for Disaster: _____

Allergies and Procedures to be Avoided

Allergies	Reactions

To be avoided	Why?
<input type="checkbox"/> Medical Procedures:	
<input type="checkbox"/> Medications:	

Diagnoses and Current Problems

Problem	Details and Recommendations
<input type="checkbox"/> Primary Diagnosis	
<input type="checkbox"/> Secondary Diagnosis	
<input type="checkbox"/> Behavioral	
<input type="checkbox"/> Communication	
<input type="checkbox"/> Feed & Swallowing	
<input type="checkbox"/> Hearing/Vision	
<input type="checkbox"/> Learning	
<input type="checkbox"/> Orthopedic/Musculoskeletal	
<input type="checkbox"/> Physical Anomalies	
<input type="checkbox"/> Respiratory	
<input type="checkbox"/> Sensory	
<input type="checkbox"/> Stamina/Fatigue	
<input type="checkbox"/> Other	



Sample Medical Summary and Emergency Care Plan

Six Core Elements of Health Care Transition 2.0

School and Community Information			
Agency/School	Contact Information		
	Contact Person:	Phone:	
	Contact Person:	Phone:	
	Contact Person:	Phone:	
Special information that the youth or family wants health care professionals to know			
_____ Youth signature	_____ Print Name	_____ Phone Number	_____ Date
_____ Parent/Caregiver	_____ Print Name	_____ Phone Number	_____ Date
_____ Primary Care Provider Signature	_____ Print Name	_____ Phone Number	_____ Date
_____ Care Coordinator Signature	_____ Print Name	_____ Phone Number	_____ Date

Please attach the immunization record to this form.

HEALTH RECORD PRIVACY

YOUTH & YOUNG ADULTS

As you grow older, it's normal to want more freedom and privacy. Your health care provider may ask to speak with you alone, while your parent/caregiver waits in another room. This lets your provider talk directly with you, and lets you talk about things you may not want to talk about in front of a parent.

To make sure this conversation is private, you can make your own MyChart account. The only information parents/caregivers can see are your immunization records. If your parent/caregiver needs to use MyChart because of your health issue, CHSC staff will ask them to sign an Incapacitated Access form.

Decision-making is a skill that takes practice and experience. Practicing this skill now will help you make informed choices as you grow up.

Helpful Tips

- When you turn 18, you are in charge of your own health care decisions. You will be the only one who can see your health information.
- If you want, you can ask your family or others to help you make health care decisions and know your health information. To do this, you must sign a form to tell staff that they can involve these people in your care.
- If you need more support, some options include:
 - Supported decision making
 - Health care power of attorney
 - Legal guardianship



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 cannot 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.
- If you need help making decisions, talk to your family, your support team, or 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 know you need **extra** support managing your health or making decisions, the [National Resource Center for Supported Decision-Making](#) has information to connect you with resources in your state.

PLANNING FOR A HEALTH EMERGENCY

YOUTH & YOUNG ADULTS

Preparing for a health emergency is important for all people. It can be even more important for people with special health care needs. All of us have basic needs – safe food, water, shelter, and things like going to the bathroom, bathing, and communicating. Emergencies can be scary, but there are things you can do to prepare for acting quickly and staying calm during emergency situations.

Helpful Tips

- Talk to your parent/caregiver about what to do in case of an emergency
- Learn about the symptoms or signs that mean you need to call 911 and how they are different from symptoms that can wait long enough for your next health care appointment
- Use the Preplowans book to make an emergency plan and build an emergency kit
- If applicable, make sure you are always wearing your health alert bracelet and have an In Case of Emergency (ICE) contact on your cell phone
- Tell the police and fire department about your health issues so they know how to help if there is a crisis
- Practice how to tell others about your health issues and medications
- Always carry your ID and health insurance card with you

Helpful Resources

- Iowa's University Center for Excellence in Developmental Disabilities

Preplowans Book

- <https://chsciowa.org/sites/chsciowa.org/files/resource/files/prepiowansbook.pdf>

FILLING OUT HEALTH CARE FORMS

YOUTH & YOUNG ADULTS

As you get older, your parent/caregiver will not always be able to fill out forms when going to your health care provider visits. It will become important for you to know your health history, your family's health history, and who can see your health information.

Helpful Tips

- Knowing what to expect can make filling out health care forms less confusing. Make sure to have the following documents with you when you go to your provider visits:
 - Health insurance card
 - ID card
 - Shared Plan of Care (if you have one)
- With your parent/caregiver take some time to review what will happen when you go to a provider visit:
 - When you get to the clinic, a staff person will greet you and your family, if they are with you. They may give you these forms (or others):
 - **Consent to Diagnose and Treat Form** – This form gives staff permission to examine you, make a diagnosis, and treat your health issue. Depending on your age, you or your parent will be asked to sign this form, date it, and say what their relationship is to you.
 - **Registration and Health History** – This form lets you change your address, phone number, and insurance information (if needed). It also asks you to list ALL of your health issues, medications, or allergies.
 - **HIPAA (Health Insurance Portability and Accountability Act) Form** – This form allows patients to decide who can see their health information. Ask the provider's office to share information with your insurance company but start thinking of other people you might want to share this information with. A parent/caregiver cannot access the health information of someone over the age of 18 unless they are named on the HIPAA form or legal arrangements have been made.
- A staff person may make a copy of your insurance card.
- Fill out the health care forms while you wait for the provider. Carefully read the forms and write as neatly as you can. If you have questions or run out of time, let a staff person know.

MAKING HEALTHY CHOICES

YOUTH AND YOUNG ADULTS

Staying healthy as you get older will allow for you to have more freedom in making your own choices, as well as prevent other health issues from developing.

Helpful Tips

- **Exercise**

- Exercise helps your whole body. It causes the body to make chemicals that can help you feel good, sleep better, and lowers the risk of some health problems.

- **Substance Use**

- As you get older, it will be up to you to decide whether to use alcohol, tobacco, and marijuana. Even though it might seem like everyone else is using them, not everyone is. You can say no without a reason, blame your parent or another adult, or arrange with your parent/caregiver to pick you up if you need help.

- **Self-Esteem**

- Self-esteem is about how much you feel you are worth and how much you feel others value you. Feeling good about yourself can affect how you feel and how you act.
- People with high self-esteem know themselves well. They are realistic, allow themselves to make mistakes, and find friends that value them for who they are. Knowing what makes you happy and how to meet your goals can help you feel strong and in control of your life.

- **Nutrition**

- Eat at least five servings of fruit or vegetables each day. Try to eat a rainbow of colors to give your body the nutrients it needs!

- **Sexual Health**

- Although it might be uncomfortable, talk to your parent, caregiver, or other trusted adult about what a healthy, consensual relationship looks like.
- Talk to your parent, caregiver, or other trusted adult about puberty and the changes you will start seeing in your body. Talk about how to take care of your body and what good personal hygiene looks like.

- **Sleep**

- Stay active during the day, as it will help you become tired and have better sleep.
- Avoid alcohol and drugs, which may disrupt sleep and increase your chances of waking up in the middle of the night.
- Avoid excessive electronic use at the end of the day to shut your brain off and help you fall asleep (and stay asleep) faster.

MAKING APPOINTMENTS, CHECKING IN, AND COMMUNICATING WITH PROVIDERS

YOUTH & YOUNG ADULTS

As you grow older, it's normal to want to have more freedom and privacy about your health and health care choices. You are the expert of what is going on with your body, so make sure to voice any concerns that you have with your provider! If you do not voice concerns, your provider may not know that something is bothering you. You will receive assistance from clinic staff during your visit, but you should make sure to ask questions if you do not understand something. The health care transition will be a change for you, but also for your caregiver(s). Make sure to ask them questions!

Helpful Tips:

- Allow yourself to try new things, make mistakes, and learn from those mistakes.
- Depending on your age, the provider might ask to speak with you alone while your caregiver waits in the hallway. This is a normal part of growing up. Use this time alone with the provider to share any concerns you may have.
- With a caregiver or trusted adult, practice making an appointment, checking yourself in, and speaking up during the visit.
- You may only have 15 minutes with the provider during your visit. Practice what you want to tell the provider and make a list of your questions.
- At the end of the visit, you may need to check-out. This may include paying a co-pay or scheduling a future visit. Try to practice these skills with an adult.

TIPS FOR FINDING AND USING ADULT HEALTH CARE

As young people grow from childhood into adulthood, many will move from being cared for by pediatricians to being cared for by adult providers. Moving to a different town due to school or a change of employment will also create a need to find a new doctor, especially if you have chronic health conditions. Follow these tips to find a provider that will meet your medical needs, is covered by your health insurance, and will give you the care you are looking for.

Before you start looking for a new provider, think about what you want:

- **Provider's Office**
 - Is the office location important?
 - Will you need help with transportation to appointments?
 - Do you need an office that is wheelchair accessible or other special assistance at the office?
 - Are the office hours convenient?
 - How will you contact the office when they aren't open?
 - What hospital do you want to use, and is this doctor on the staff there?
- **The Provider**
 - Do you want someone who will take time with you during an office visit or are you comfortable with someone who is "good" in their field but lacks bedside manner?
 - Is it important that your new provider is knowledgeable about your special health care needs or do you think you can provide that information or connect the new doctor with those who can provide medical insight?

Since your wellness depends on the medical services you receive, it is important that you are comfortable talking with your new provider and feel that they understand your concerns. Consider scheduling a "get-acquainted" interview before you make a final choice of a new provider. You will have to pay for this visit, as it is NOT covered by insurance benefits. This interview should last 15-30 minutes, and the best time to see a provider is when your health condition is stable, so you are not asking for crisis care.

TIPS FOR FINDING AND USING ADULT HEALTH CARE CONTINUED

Think about (and write down) questions that are important to you:

- Is the provider knowledgeable about your health issues and/or willing to learn from you and from previous providers?
- Do you like the communication style with the provider and the office?
- Are you satisfied with office practices and access during an emergency or in urgent situations?
- Do you have access to hospitals and specialists if you need them?

Providers who care for children are different from providers who care for adults. As a young adult, you will need the following skills as you transition from pediatricians to adult health care providers:

- Ability and willingness to tell the provider about your history, current symptoms, lifestyle, and self-care in a few minutes. Remember to bring you medical history summary to your appointment.
- Ability to ask questions about your condition and how it will affect your school, work, recreation, and social life.
- Ability to tell the provider about your needs for education, technology, and accommodations.
- More independence in following up with referrals and keeping all agencies informed.
- More involvement in keeping yourself healthy with diet and weight control, exercise and recreation, following medication, treatment and hygiene regimens, limiting risky behaviors (drinking, smoking, unsafe sexual practices), and getting help for your mental health.
- Being more aware of your physical and mental symptoms and health needs before you experience a crisis.
- Developing a plan for when you have an emergency.
- Understanding health care benefits and health insurance.
- Recognizing that as you become more capable in directing your care, that you – not your parents – should be in charge of your health.

Adapted from the KY Commission for Children with Special Health Care Needs (2001)

Role Play Example: Paperwork at the Sign In Desk

1. Sample "HIPAA" and the "Consent to Treat" forms are placed on a clipboard and given to the individual who plays the role of the office receptionist. The sample insurance card is given to the individual who plays the role of the patient.
2. Using the following script, practice the back and forth exchange that occurs when signing in for a medical appointment. Practice signing and dating the forms. Reverse roles and repeat.

You Will Need:

- Clip board
- "HIPAA" form
- "Consent to Treat" form
- Insurance card
- Pen or pencil

YOU

Hello, my name is: (say your name)
I have an appointment at (say time of your appointment)
I am here to see (say name of your doctor)

Ok, let's take care of some paperwork:

Signing the "Consent to Treat" form gives us permission to provide medical care. The "HIPAA" form gives us permission to share your health information with the insurance company and with any other people that you list on the form.

**Office
Receptionist**

YOU

(Give receptionist your insurance card)
I would like to list someone on my HIPAA form.
Where do I add that information?

You can list people in this section.

(Receptionist indicates section on the HIPAA form)

Signing the form gives us permission to share your health information with anyone who is listed in this section.

(Receptionist copies insurance card for office records)

**Office
Receptionist**

YOU

Thank you!
(Remember to sign and date the forms. Be sure the receptionist remembers to return your insurance card!)

How to use the Role-Play Template: Use this template as a script with 2 or more individuals, or use the blank template to customize scenarios. The insurance card and a clip board with the "HIPAA" and "Consent to Treat" forms are used as props. Have individuals practice signing the forms. Reverse roles and repeat. Use the "confidence meter" before and after each role-play session to track progress.

Benefit Card

NEW YORK STATE
BENEFIT
IDENTIFICATION CARD

NEW YORK STATE SEAL

ID NUMBER: AB12345C CARD NUMBER: 123456 1234 5678 111 01

SEX: F DOB: 11/11/1992

LAST NAME: SARAH

FIRST NAME: JONES

ISO#100123

ACCESS NUMBER: 1234 1234 123

SEQ# 01

Sarah Jones

ID Number

Last Name

First Name

Card Number

ISO Number

Access Number

SEQ Number

How to use the Benefit Card Use this sample New York State Benefit card to become familiar with the information that is included on an Insurance card. You can also use it as a prop during role play when you practice signing in at the doctor's office. There is an unlabeled card at the end of the chapter. Circle the ID number and the card number. Try to find this information on your own insurance card.

HIPAA Form

**New York State Department of Health
HIPAA Compliant Authorization for Release
of Medical Information and Confidential
HIV* Related Information**

Patient Name: _____
DOB: _____
Telephone Number: _____

(This form has been approved by the New York State Department of Health)

Patient Address: _____

I, or my authorized representative, request that health information regarding my care and treatment be released as set forth on this form. In accordance with New York State Law and the Privacy Rule of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), I understand that:

1. This authorization may include disclosure of information relating to ALCOHOL and DRUG ABUSE, MENTAL HEALTH TREATMENT, except psychotherapy notes, and CONFIDENTIAL HIV*RELATED INFORMATION only if I place my initials on the appropriate line in item 8. In the event the health information described below includes any of these types of information, and I initial the line on the box in item 8, I specifically authorize release of such information to the person(s) indicated in item 7.
2. If I am authorizing the release of HIV-related, alcohol or drug treatment, or mental health treatment information, the recipient is prohibited from redisclosing such information without my authorization unless permitted to do so under federal or state law. I understand that I have the right to request a list of people who may receive or use my HIV-related information without authorization. If I experience discrimination because of the release or disclosure of HIV-related information, I may contact the New York State Division of Human Rights at (212) 480-2483. This agency is responsible for protecting my rights.
3. I have the right to revoke this authorization at any time by writing to the health care provider listed below. I understand that I may revoke this authorization except to the extent that action has already been taken based on this authorization.
4. I understand that signing this authorization is voluntary. My treatment, payment, enrollment in a health plan, or eligibility for benefits will not be conditions upon my authorization of this disclosure.
5. Information disclosed under this authorization might be disclosed by the recipient (except as noted above in [item 2]), and this redisclosure may no longer be protected by federal or state law.

6. Name and address of health provider or entity to release this information: _____

7. Name and address of person(s) to whom this information will be disclosed:
a) _____
b) _____
c) _____

8. Specific information to be disclosed:
 Oral disclosure of medical information from (insert date) _____ to (insert date) _____
 Complete copy of Medical Record OR check all that apply:
 discharge summaries office notes (except psychotherapy notes) test results radiology reports x-ray films
 billing records Other: _____
Copies of Medical Record for Dates of Service From: (insert date) _____ to (insert date) _____
Include: (indicate by initialing) _____ Alcohol/Drug Treatment _____
_____ Mental Health Information _____ HIV-Related Information _____

9. Reason for release of information:
 At request of individual
 Other: _____

10. This authorization will expire upon:
 Revocation
 Date/Event: _____
 One Time Release

11. If not the patient, name of person signing form: _____

12. Authority to sign on behalf of patient: _____

All items on this form have been completed, and my questions about this form have been answered. In addition, I have been provided a copy of the form.

Signature of patient or representative authorized by law _____ Date: _____

* Human Immunodeficiency Virus that causes AIDS. The New York State Public Health Law protects information which reasonably could identify someone as having HIV symptoms or infection and information regarding a person's contacts.

Your name

Your date of birth

Your phone #

Your address

Who will give out your information

Who will get your information

Decide how your health information can be shared. The providers can talk with each other OR they can share copies of your entire medical record, or parts of your record (you decide)

Initial here if it is OK with you to share information about alcohol/drug treatment, mental health care and/or HIV related information

Give reason for sharing information, decide and indicate here how long information can be shared

If you have a health guardian he/she signs here

Today's date

Sign your name here!

Consent to Treat Form

Consent to Diagnostic and Medical Treatment

CONSENT TO DIAGNOSTIC AND MEDICAL TREATMENT

I know that for my child _____ may have a condition that requires medical care, and willingly give permission to such care in The Hospital. I also understand that this care may include routine diagnostic procedures and medical treatment. As part of this care, I give permission for any blood, urine, tissue or other body samples to be used for diagnosis or treatment. I also agree that these samples may be used for scientific purposes after all necessary diagnostic tests have been completed and after The Hospital removes all my personal information. No promises have been made to me about the result of treatments or examinations that I will have while I am in the hospital. I understand that if I decide to leave the hospital without being formally discharged, that this means I am withdrawing my request for treatment.

FINANCIAL AGREEMENT

I agree to assume full, primary responsibility for payment of all charges for services I receive from The Hospital and any physician or physician organization performing services at The Hospital and are not paid by my insurance company or other party. I give permission to The Hospital and any physician or physician organization performing services at The Hospital and its agents to disclose my protected health information to my insurance company or others as necessary to obtain payment for services, including confidential HIV-related information. I agree to pay any amount of money I owe for the services within 30 days after I receive a bill. I give permission to The Hospital and any physician or physician organization performing services at The Hospital to review my credit reports if a balance of the bill remains unpaid after 30 days.

ASSIGNMENT OF BENEFITS

I assign to The Hospital and any physician or physician organization performing services any monies and benefits payable to me under any health insurance or other insurance policy, governmental program, or other party providing benefits for all or a part of the services provided. I agree that any credit balance after payment from such sources may be applied on any account at The Hospital and any physician or physician organization performing services at The Hospital. I certify that the information given regarding my insurance is correct and current. I agree to pay The Hospital and any physician or physician organization performing services at The Hospital within 30 days of receiving any payment made directly to me by my insurance company or other party that is connected to charges for Hospital services. I agree to complete any forms necessary to obtain payment or assignment of such monies or benefits. I give permission to The Hospital and any physician or physician organization performing services at The Hospital to request payment for services for no-fault benefits, workers compensation benefits, or any other benefits available to me under any governmental programs for any unpaid balance of my hospital bill. This will be done for me if I am eligible for benefits and do not submit a request for payment of services from these governmental programs.

Patient Name: _____

Sign Here _____

MR#: _____

Date: _____

Print patient name

Sign here!

Today's date

How to use the forms

Practice signing and dating the HIPAA and Consent to Treat forms.

Role Play Example: Scheduling an Appointment

1. Gather the items you will need to make an appointment at your doctor's office:
2. Using the following script, practice making a phone call with a partner who acts the role of a doctor's office receptionist.
3. Write down the information you receive in your calendar. Reverse roles.

You Will Need:

- Cell phone
- Pen
- Calendar
- Your insurance card/number
- Your doctor's name and phone number.

YOU

Hello, my name is: (say your name)

I would like to schedule an appointment with Doctor _____

What is your date of birth?
What is your insurance number?

Monday March 2nd at 2:00 is available.

**Office
Receptionist**

YOU

Check Your Calendar. If this day/time is not good for you say:
I can't make that. Do you have another date/time available?
If you need accommodations (like a lift or translator) say:
Can your office accommodate my need for a _____

The receptionist will answer your questions as you ask them.
Make sure to write the answers down in your calendar.

**Office
Receptionist**

YOU

Before you hang up the phone:

Repeat the information back to the receptionist:

My appointment is with _____ on _____

Thank you for your help

How to use the Role-Play Template: Use this template as a script with 2 or more individuals. Cell phones and a calendar or appointment book can be used as props. Individuals may also use the blank template to customize scenarios. Have individuals practice listening and writing down information. Reverse roles and repeat. Use the "confidence meter" before and after each role-play session to track progress.

Calendar • Benefit Card

JULY

SUN	MON	TUE	WED	THU	FRI	SAT
		1	2	3	3	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

Date and time of appointment:
July 10
1:30 p.m.

What the appointment is for:
To find out why I have an earache

Doctor's Name: *Dr. Miller*
Doctor's address: *25 Main Street*
Doctor's Phone#: *44-4321*

Transportation: *Medicaid taxi*
Pick up time: *12:15*
Number to call if there is a problem:
44-1234

Activities
 Datarfile
 Contacts

ID Number

Last Name

First Name

NEW YORK STATE

BENEFIT

IDENTIFICATION CARD

ID NUMBER: AB12345C CARD NUMBER: 123456 1234 5678 111 01

SEX: F DOB: 11/11/1992

LAST NAME: SARAH
 FIRST NAME: JONES

Sarah Jones

ISO#100123 ACCESS NUMBER: 1234 1234 123 SEQ# 01

Card Number

ISO Number

Access Number

SEQ Number

How to use the Calendar and Benefit Card Use this calendar and benefit card as a guide during role play to practice writing down the date and time of an appointment and to become familiar with your benefit card. There is a blank calendar and an unlabeled Medicaid card at the end of the chapter to practice with, or use your real ones.

TRANSPORTATION TO MEDICAL APPOINTMENTS

YOUTH & YOUNG ADULTS

As you get older, you may need to start learning the skills to be able to get to medical appointments or other places around town. There may also come a time when your parents or caregivers can no longer attend or physically take you to your appointments, so starting to learn how to navigate transportation will be important for your future.

Helpful Tips:

- Brainstorm methods of transportation that you can use and have available to you. Some choices include walking, riding a bike, scheduling a ride with their insurance company, taking a city bus, or driving themselves or with a trusted adult.
- Use the internet or a phone book to find the address of the clinic and the best route to get there.
- Practice how to get to the appointment ahead of time and keep track of how long it takes to get there.

UNDERSTANDING MEDICATIONS AND GETTING REFILLS

YOUTH & YOUNG ADULTS

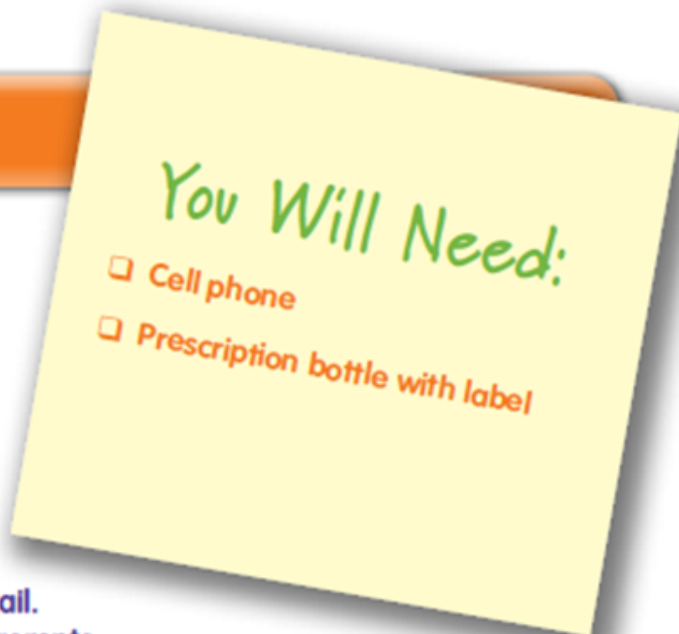
You are the expert in understanding how medications affect you. Making sure that you continue your medications as you transition to adulthood will be important in managing your symptoms and your health conditions. Learning the skills to advocate for yourself at your provider's office will help you share important information about the effects your medications are having on you.

Helpful Tips:

- Have an adult help you learn the names of your medications. Some medications have brand and generic names, so ask your provider if you can use the generic version.
- Ask your caregiver or provider teach you the reason for why you need to take your medications and how your medications help your health issue.
- Remember to tell your health care provider if you have any trouble taking your medications or if you experience any side effects.
- Bring any prescriptions, over the counter medications, and supplements (if applicable) to your appointments.
- Make a Medication List that includes:
 - Name of the medicine
 - How much you take (dose)
 - Time of day you take the medication
 - Why you are taking the medication
 - What happens if you skip the medication
 - Possible side effects or other medications that might impact the way your medicine works

Role Play Example: Calling in a Prescription Refill

1. Gather the items you will need to call in a prescription refill.
2. Using the following script, practice making a phone call with a partner who acts the role of the pharmacist.
3. Reverse roles and repeat.



YOU

Many pharmacists use voice mail.

You can follow the voice mail prompts:

“To refill a prescription press 1” (press 1 on your keypad)

“Use the touch pad on your phone to key in the prescription number followed by the pound sign.” (enter prescription number on label)

Or simply press “0” to speak with the pharmacist

Hello, my name is (say your name)

I would like to call in a prescription refill.

Do you have your prescription number?

Pharmacist

YOU

Check your prescription label and give information:

My prescription number is: (read number from prescription label)

When will my prescription be ready?

The pharmacist will tell you when your prescription will be ready.

He may ask you if you want it delivered or if you will pick it up.

Pharmacist

YOU

Tell the pharmacist how you will get your prescription:

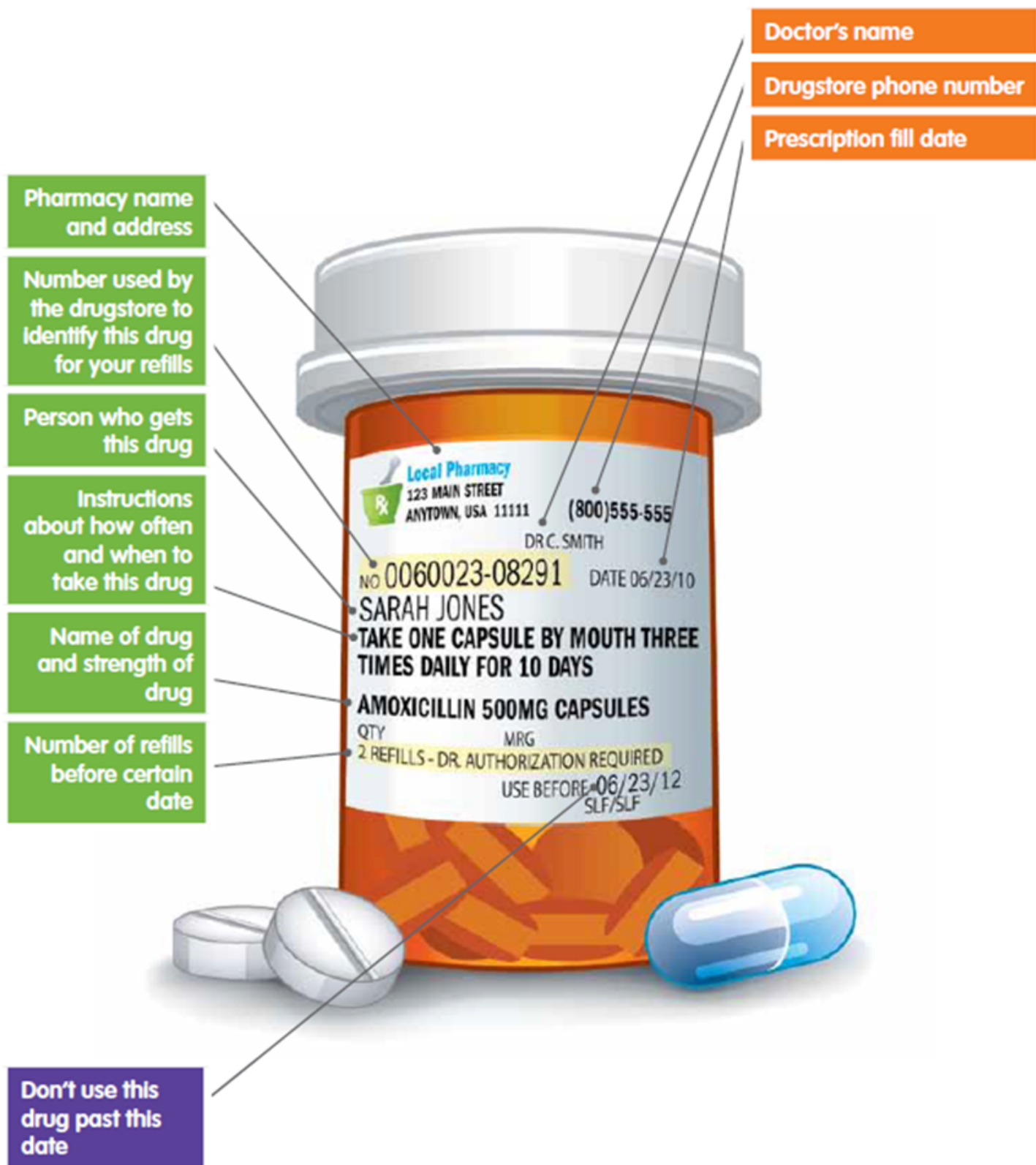
“Yes. I’d like to have the prescription delivered please”

or

“Thank you, I will pick it up”

How to use the Role-Play Template: Use this template as a script with 2 or more individuals. Cell phones and a prescription bottle can be used as props. Individuals may also use the blank template to customize scenarios. Have individuals practice reading information from the prescription label. Reverse roles and repeat. Use the “confidence meter” before and after each role-play session to track progress.

Prescription Label



How to use the Prescription Label

Familiarize yourself with all of the information that is included on a prescription label.



Filling a Prescription

To Fill a Prescription (the medicine your doctor ordered)

- Fill your prescription at the pharmacy or drugstore as soon as you can and start taking the medicine right away.
- Make sure the pharmacist knows all the medicines you take, including over-the-counter medicines like Tylenol or cold medicine.
- You may need to pay something (co-pay) to get your medicines.
- Ask questions to be sure you understand how to take your medicine and know what side effects to watch for. Don't sign for your medicine until you understand.
- If the pharmacy does not have the medicine your doctor has ordered or your insurance doesn't cover it, ask the pharmacy to call your doctor to discuss options.
- Make sure you are given the correct medicine.



Refilling a Prescription (getting more of the same medicine)

- Know how you will order your refill:
 - **In person** - go to the pharmacy.
 - **By phone** - call the phone number on your medicine bottle to order a refill. You might get a recording that prompts you to press your prescription number and the time and date you will pick up your refill.
 - **By mail** - some insurance companies have mail-order choices that provide a three-month supply. If you want to use this option, you will need to ask your doctor to include a three-month supply on the prescription order. This may be cheaper.

When to Get Your Refill

- Keep track** (use a calendar, a pill sorter, or other reminder) of when you need to get refills to avoid running out and missing a dose of medicine. Missing doses can be bad for your health.
- Check the label** on your medicine bottle to see how many refills you can get before your doctor will need to give you a new prescription.
- Start your refill request about a week before running out of your medicine.** This routine will allow time to resolve any problems you may run into, such as insurance authorization, physician contact, or pharmacy supply.
- Plan ahead: you may need your refill sooner than expected** (for example, if your dose changes or you need an extra supply to bring on vacation).

(Turn over for more tips and examples on filling a prescription)



When Filling a Prescription

Pharmacy Name _____

Phone Number _____



Be ready to provide:

- ✓ Your name
- ✓ Name of medication
- ✓ Doctor's name
- ✓ Your insurance information
- ✓ Your prescription number (if refill)
- ✓ Date and time you will pick up your prescription

Here is an Example Script for Getting a Prescription

YOU: "Hello, I need to fill this prescription." (*Give the prescription to the pharmacist*)

Pharmacist: "What is your name?"

YOU: "My name is _____." (*State your full name*)

Pharmacist: "What is your birthdate?"

YOU: "---- / ---- / ----." (*State month/day/year of your birthdate*)

Pharmacist: "What is your insurance information?"

YOU: _____ (*Give your information from your insurance card*)

Pharmacist: "The prescription will be ready in 15 minutes. When will you pick it up?"

YOU: "_____." (*State preferred pick up time*)

Pharmacist: "Do you have any questions?" (Examples: "Do I need to take this medicine with food? How long should I take this for? Are there side effects I should be aware of?" etc.)

YOU: "_____."

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Take Medications As Directed

Things to Know About Your Medicine



- Make sure you know the exact name of the medicine(s) you take (brand and generic).
 - Some medications have brand and generic forms. Ask your doctor if it is alright to substitute with generic form.
 - Learn why you need to take each medicine (how it treats your condition).
 - Take your medicine at the same time every day. Taking your medicine at a specific time such as 10:00 p.m. might be better than bedtime if your bedtime changes. Work with your doctor to set a schedule that works for you.
-
- Ask your doctor or pharmacist if you have questions about taking your medicine.
 - Let your doctor know if you have trouble taking your medicines (hard to swallow, forget to take, upset stomach, other problems).
 - Side effects can be bothersome and dangerous - make sure you know what to look for.
 - Don't take too much or too little medication. Know how much to take, when you can take more, and which medicines can be taken together.
 - Whenever you go to a doctor or to the hospital, always bring your medications or a list of your medications, including non-prescription medications.
 - Keep track of when you need to refill your medicines and call the pharmacy for your refills.
 - Keep your list of medicines with you.

Find a Way to Remember to Take Your Medicines

You may want to use medication reminders:

- Take at the same time you do another daily routine (with breakfast, brush your teeth, watch a daily TV show).
- Set up a text message or cell phone alarm.
- Use an alarm-vibrating pillbox, pill organizer, automatic pill dispenser, time watch, or alarm pocket watch. To find the right system for you:
 - ✓ Ask your pharmacist.
 - ✓ Check with your local medical supply stores.
 - ✓ Search the web using search words such as pill alarms, automated medication dispenser, e-pill, or pill timer.

(Turn page over to begin your medication list)



Medication List

(Please use pencil to complete this form.)

Name: _____

- Ask your physician or pharmacist to help you complete this list.
- Read the label on each medicine for directions on how to take and for possible side effects/danger signs/interactions. For more information see drug sheets.
- Whenever you see the doctor, including your primary care physician and any specialists, review and update this medication list.
- After hospitalizations, always review your medication list with your doctor.

Medicine	Dosage (how many you take)	Time (when you take it)	Why You Take It	What Happens If You Skip It	Possible Side Effects

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UNDERSTANDING HEALTH INSURANCE

YOUTH & YOUNG ADULTS

Having consistent health insurance coverage is an important part of transitioning to adult health care. Health insurance helps pay for appointments, medications, hospital care, and special health equipment. Health insurance is also important when you are NOT sick. Screenings, immunizations, and mental health care can help you stay healthy as you get older.

Health Insurance Definitions

- **Co-Insurance:** The patient or policyholder's share of the costs of a covered health care service. It is a percent of the amount the insurance company allows for the service. You pay the co-insurance plus any deductible you owe.
- **Co-Pay/Co-Payment:** The amount you might have to pay for a covered service. This is often paid at the appointment.
- **Deductible:** The amount you owe for health care services before your insurance pays. For example, if your deductible is \$1,000, your insurance company won't pay anything except for preventative care until you meet the \$1,000 deductible.
- **Premium:** The amount that must be paid for your health insurance. You, your employer, and/or the policyholder pays this amount monthly, every few months, or yearly.
- **Network:** The clinics, doctors, and suppliers your health insurance company has agreements with to provide health care services. Ask your insurance company which providers are in-network. If a provider is out-of-network, it might cost more for you to see them.

Helpful Tips:

- If possible, have your parent/caregiver help you understand your insurance coverage and what the terms mean.
- Start thinking about what insurance you might qualify for when you turn 18. The type of insurance you get may greatly depend on your health care needs and the government programs you qualify for.
- Ask your insurance company for:
 - The costs of seeing a provider in-network and out-of-network
 - The costs of medications under this specific insurance policy
 - The limit on the number of visits for certain services (such as physical therapy or home health care) and any rules for getting approval to see a specialist or go to the hospital
- If you currently have Medicaid, you must reapply as an adult about 3 weeks before you turn 19.

HEALTH INSURANCE 101

HELPFUL TIPS TO REMEMBER

Learning Your Insurance Benefits

- Use providers who are in your network and be sure that your insurance benefits will cover as much of the cost as possible
- Begin to learn more about what services are covered by your insurance. Know your plan's deductible(s) and co-payments. This will be in your policy book.
- Always carry your own copy of your current insurance card.
- Find out if you need a referral from your primary care provider before you go to a new doctor or specialist.
- Find out if your insurance company will pay for your equipment to be fixed and/or replaced if necessary.
- Read about the appeal process in your policy book and use it when you think services have been denied in error.
- Before turning 18 years old, check what age your current plan coverage will end and apply for adult health insurance before your coverage ends.

When Contacting Your Insurance Company, Be Ready to Provide:

- Your name
- Date of birth
- Identification number (on your insurance card)
- Relationship to the policyholder (self, child, parent, etc.)
- Policyholder's date of birth, address, and phone number
- Date of service
- Reason you are calling
- If available, a reference number (on the Explanation of Benefits or letter from insurance)
 - This is usually emailed or mailed to you

Keep Track of Insurance Information

- Keep track of phone calls with your insurance company. Write down the date, the number you called, who you talked to, what you talked about, and what is going to happen next.
- Follow up to make sure issues/problems are resolved.
- Keep all insurance information where you can easily find it. Save information, such as Explanation of Benefits forms, eligibility and denial letters, and notices regarding a change in covered or excluded services, deductibles, co-payments, or out-of-pocket costs.

FINDING ADULT HEALTH CARE PROVIDERS

YOUTH & YOUNG ADULTS

A Primary Care Provider (PCP) is a provider you can see for regular check-ups, vaccines, when you don't feel well, or for health issues that you don't need a specialist for. Regular check-ups with a PCP can help catch problems early on. If you need to see a specialist, a PCP can often refer you to someone that can help.

Pediatricians are typically only trained to see patients until the age of 21. You may develop health concerns as you get older, and you may also develop other health conditions that are more common in adults. If you are currently seeing a family doctor and you want to keep seeing them as an adult, you do NOT need to switch to a new PCP. If you are currently seeing a pediatrician, your current provider may help you find a new PCP that serves adults with your condition. This conversation with your PCP usually happens around ages 17-21. Even if you are seeing a family doctor, you might need to find new specialists that can better serve adults.

How to Find Adult Providers

- Ask your current provider for a referral
- Consider your parent's primary care provider as someone that you could see
- Call your insurance company
- Check with your local support groups
- Call large medical and specialty rehabilitation hospitals and ask for a referral line
- Ask your Care Coordinator or Case Manager for suggestions
- Ask friends for suggestions

FINDING ADULT HEALTH CARE PROVIDERS

YOUTH & YOUNG ADULTS (CONTINUED)

Questions to Ask

It is important to find a provider that makes you feel comfortable and that can meet your unique needs. Before you choose a new provider, call their office and ask to speak with a staff member who has time to answer your questions, or make an appointment to meet the provider and staff in person.

Ask the Office:

- Does the provider accept your insurance coverage? Are they taking new patients?
- Is the office accessible (easy to reach and easy to get around inside the building or clinic area)?
- What are the office hours? How can the provider be reached after hours?
- How will the provider exchange information with your specialists?
- Will the office be flexible to meet your health needs (allow service dog, schedule visits so you will not miss a meal, or schedule at quiet times if you are sensitive to noise)?

Ask the Provider:

- Is the provider willing to discuss your health history and special needs with your pediatric provider?
- Does the provider currently see patients with health conditions similar to yours?
- At what hospital does the provider schedule procedures?
- Where did the provider get their medical school and specialty training? Are they board certified?
- Does the provider have any special interests or more advanced training?

Ask Yourself:

- Does the provider listen to me and my family or are they constantly interrupting us?
- Can the provider explain information in a way that my family and I can understand?
- Does the provider take enough time to answer our questions?
- Does the provider treat my family and I with respect?

MAKING THE MOST OF YOUR VISIT WITH YOUR PROVIDER

YOUTH & YOUNG ADULTS

As you have grown up, your parents or caregivers have probably done most of the talking at your appointments. As you get older, you will want to start speaking up at these visits. Talking to providers (doctors, nurses, specialists) may seem overwhelming and difficult, but it will get easier the more you practice.

Helpful Tips:

- You may only get 15 minutes for an appointment. If you have a lot to talk about or need more time to speak, ask the secretary to schedule your appointment for a little longer.
- Show up about 15 minutes early to give you time to check in before the appointment.
- Ask your parent or caregiver to wait outside the exam room so you can have a few minutes to talk to the provider alone.
 - This allows you to talk about anything you need to
 - It will also help you get used to talking to a provider on your own
- Write down a few of your own questions or things you want to tell the provider before the visit. It can be easy to forget things you want to ask.
- Write down what the provider says or ask if you can use your phone to record instructions to help you remember later.
- Ask questions!
 - If you don't understand what the provider says, ask them to explain it again or explain it in a different way.
 - Don't be shy about asking the provider to explain it again – it is part of their job and they want you to know what to do to take care of yourself.

MAKING DECISIONS AFTER AGE 18

YOUTH & YOUNG ADULTS

When you turn 18, you are legally considered an adult. This means that health care providers will begin talking to you, rather than your parents, about your health. The law that requires this is called HIPAA (Health Insurance Portability and Accessibility Act).

Helpful Tips:

- If you want to share your health information with others, the provider will need you to fill out a form that grants your parents or caregivers access to your medical record.
- If you need help making choices as an adult, talk to your family, provider, or others you trust about who needs to be involved in your care and how to include them.
- There are many choices for young adults who need help making decisions:
 - **Health Care Power of Attorney** lets a young adult choose an attorney to be their representative, or agent, in the event that they are not able to make or communicate decisions about all aspects of their health care.
 - **Supported decision-making** allows the young adult to create a team that they trust to help them understand their choices and make their own decisions.
 - **Guardianship and conservatorship** may take away all of someone's decision-making rights and can be ended only by a court order. There may be other choices that are cheaper and less restrictive but exploring all of the options will help your family make the best decision for your young adult.

Guardianship — More Restrictive Option with Alternatives

Guardianship is a formal, legal process in which a court is requested to assume responsibility for a person as a "ward" and then may appoint an "agent" to act as guardian. The guardian may or may not be a parent or family member, and the guardian's authority is determined by the judge's order or state law. The guardian may have certain responsibilities to the court i.e. submit written reports, attend additional hearings as needed, and maintain standards that preserve the ward's decision-making process, as much as possible.

Some families pursue guardianship because they believe or have been told that it's the only legal answer to concerns they may have about their young adult's ability to handle money or access and stay connected to adult or health care services. While some form of legally arranged guidance may be called for, full guardianship may not be the only option. There may be forms of guardianship that can provide temporary or specific decision-making support while not completely denying the young adult's participation in that decision. When it comes to determining what is the best option, the "least restrictive" ones may best support and promote the young adult's decision-making skills and rights.

Each state will have their own definition of guardianship options as well as laws to govern them and every young person has a unique situation and needs. In researching options, families may want to consider availability and appropriateness of options for "emergency," "temporary," "limited," or "provisional" guardianship, 90-day health care guardians, or conservators. Sometimes a combination of different and least restrictive options may be required in order to provide the best assistance.

Guiding Questions to Ask in Considering Decision-Making Support Options

In summary, in considering what the right decision making support for young adults may be, here are some key questions families may ask:

1. What kind of decision is being made?
2. Has the person made a decision like this before?
3. Has the person been assisted to understand the risks and benefits?
4. How big is the impact of this decision in the person's life?
5. How long would the person live with the decision?
6. How hard would it be to undo?
7. Most important: What is the least restrictive level of support that might work?

PROTECTING EVERY YOUNG ADULT PATIENTS RIGHT TO PRIVACY AND CONSENT

Health care providers, especially those accepting a young adult with intellectual disability into their primary care practices, must protect every patient's right to privacy and consent. Along with past medical records and health-related information, the health care provider in this situation will need accurate information regarding the individual's independent decision-making status and the names of anyone who has been appointed or identified to support decisions on the young adult's behalf.

RESOURCES FOR MORE INFORMATION ON GUARDIANSHIP AND DECISION-MAKING ALTERNATIVES:

"[Understanding Guardianship](#)": An archived broadcast of Got Transition's 2012 webinar; dcqualitytrust.org: Quality Trust for Individuals with Disabilities; thearc.org: "The Arc" for People with Intellectual and Developmental Disabilities; acf.hhs.gov: U.S. Dept. of Health and Human Services, Administration for Children and Families, State Protection and Advocacy Agencies; www.ndrn.org: National Disability Rights Network: Protection & Advocacy for Individuals with Disabilities; <http://www.guardianship.org>: the National Guardianship Association (NGA) is a resource for volunteer, family and professional guardians.

ACTIVITIES OF DAILY LIVING ASSESSMENT

Instructions: Each bold heading below refers to an Activity of Daily Living (ADL). In the column on the right side, put a check mark in the row that shows how much help you or your teen/young adult needs.

Activities of Daily Living	Which applies to you, or your teen/young adult?
1. Ability to use a phone	
Operates phone by self	
Calls a few well-known numbers	
Answers phone, but does not call	
Does not use phone at all	
2. Shopping	
Takes care of all shopping on own	
Shops on own for small purchases	
Needs help on all shopping trips	
Not able to shop	
3. Preparing Food	
Plans and makes meals on own	
Makes meals if given what they need	
Heats up prepared meals or food	
Needs someone else to make all meals	
4. Housekeeping	
Keeps home clean by themselves without help	
Washes dishes, makes beds, and puts things away without help	
Does not do any cleaning	
5. Laundry	
Cleans clothes, does laundry without help	
Needs help cleaning clothes and doing laundry	
6. Transportation	
Drives car	
Uses bus, taxi, or public transportation without help	
Needs help using bus, taxi, or public transportation	
7. Responsibility for Own Medication	
Able to take medications the right way without any help	
Takes medicines the right way if prepared by someone else in separate doses	
Needs help taking medications the right way	

ACTIVITIES OF DAILY LIVING ASSESSMENT

8. Ability to Handle Finances	
Manages money without help (pays bills, goes to the bank, works with a budget, buys things at the store)	
Able to buy things, but needs help with banking and budgeting	
Does not manage money	
9. Bathing/Showering	
Does not need help bathing or showering	
Needs help bathing or showering	
10. Dressing	
Gets dressed without help	
Needs help getting dressed	
11. Toileting	
Goes to the bathroom and wipes self after without help	
Needs reminders to go to the bathroom, or needs help cleaning up afterward	
Uses diapers, or uses a bowel management program	
12. Continence	
Stays dry during the day and night	
Stays dry during the day only; uses diapers at nights	
Uses diapers or catheter	
13. Transfer	
Can get in and out of bed or chair without help	
Needs help getting in and out of bed or chair	
14. Feeding	
Eats without help	
Eats without help, but needs help cutting up food	
Needs help to eat	
Fed using tubes	
15. Safety and Vulnerability	
No concerns about vulnerability or personal safety	
Needs supervision to monitor safety and/or is vulnerable	
16. Mental Health	
Handles emotions or moods (anxiety, happiness, sadness) in a healthy way	
Needs some help handling emotions or moods, or working through problems	
Receives mental health services from a counselor, doctor, or other therapist	

ACTIVITIES OF DAILY LIVING ASSESSMENT

17. Emergency Plan	
Family has an emergency plan (food, water, 7 days of medications, evacuation plan, etc.)	
Family does not have an emergency plan	
18. Services	
Physical Therapy	
Occupational Therapy	
Speech and Language Therapy	
Mental Health Service/Counseling	
Vocational Rehabilitation	
Waiver/Voucher Assistance	
Other?	
Continue to receive services after age 18? Please identify which ones below.	