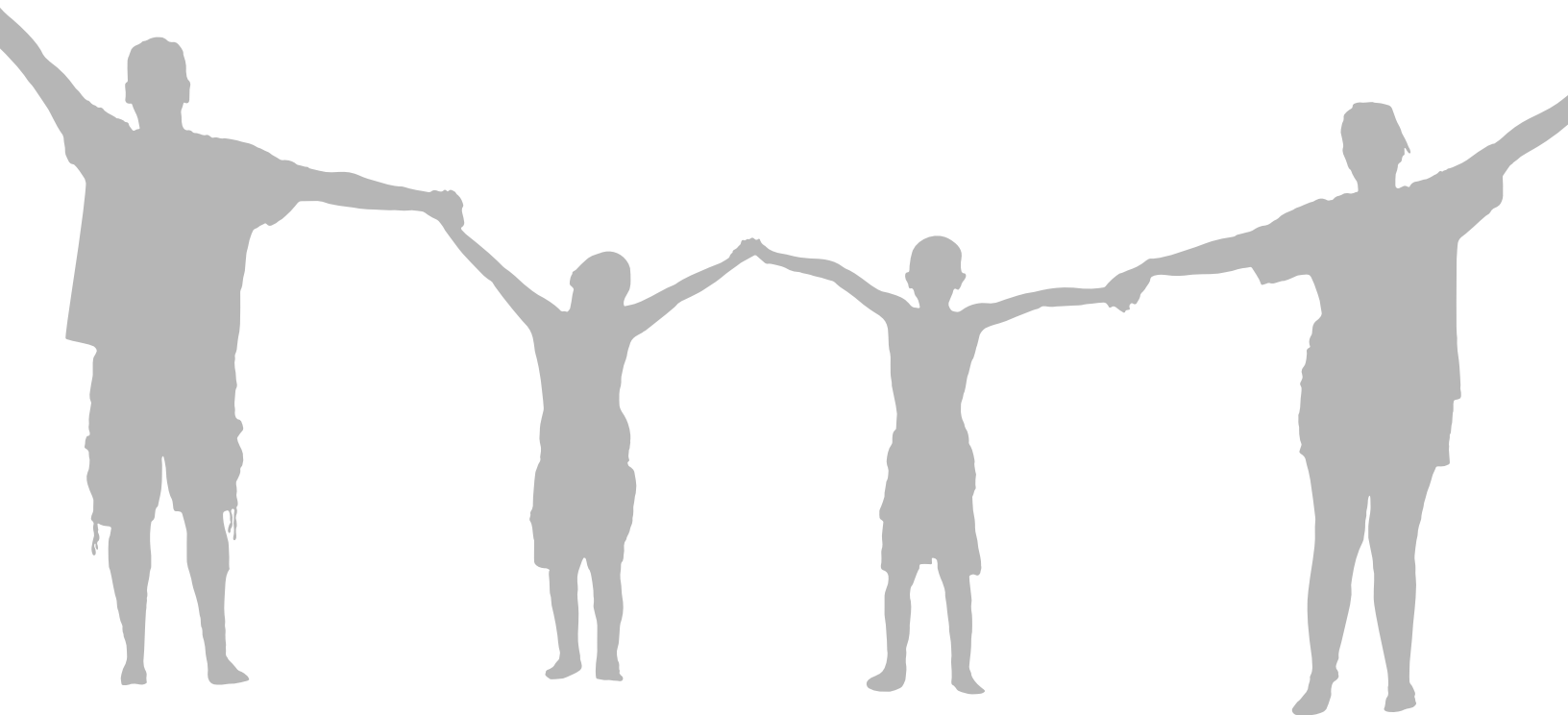

TRANSITION TO ADULT HEALTH CARE

HANDBOOK FOR YOUTH, YOUNG ADULTS, AND THEIR FAMILIES



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

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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

PARENTS & CAREGIVERS

What is Health Care Transition?

Health Care Transition is the process of preparing your youth for health care as an adult.

During childhood, you have helped your child with special health care needs manage their health in ways such as:

- Calling to set up appointments
- Completing medical forms
- Keeping track of their medications
- Advocating on behalf of your child

As your child gets older, managing those health needs may become more of their responsibility. While each child will gain various levels of independence as they enter adulthood, all youth will require an organized transition process to help them:

- Gain independent health care skills
- Prepare for an adult model of health care
- Transfer to adult health care providers

For children with special health care needs, we cannot assume that they will become fully independent in managing their health care when they turn 18. For those of you with child(ren) with complex health needs, there will be opportunities throughout this handbook to guide you as you navigate the next steps in medically transitioning your child to adulthood.

Why do we start thinking about the transition to adult health care at 12?

We begin talking about the transition to adult health care at age 12 so that youth and their families are prepared for the potential challenges that may arise with transition. Transitioning to adult health care can be time consuming and complicated, so giving yourself enough time to understand it will help you in the future.

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

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 PARENTS & CAREGIVERS OF TRANSITIONING YOUTH

Age 12-13

- Continue monitoring your child's health condition, medications, and allergies
- Ask your child's provider if, and at what age, they no longer care for young adults

Age 14-15

- With your child, discuss what they should do in case they have a medical emergency
- If it fits within your child's ability, support your child in making health care appointments and managing their prescriptions
- If it fits within your child's ability, encourage them to start seeing their health care provider alone to gain skills in health care management

Age 16-17

- If it fits within your child's ability, encourage them to make appointments, see providers alone, ask questions, and refilling their medications
- Learn about your child's health privacy rights when they turn 18
- Make a medical summary with your child's provider
- If needed, explore options for substitute decision-making to support your child when they turn 18

Age 18-21

- If applicable, learn about the substitute decision-making arrangements made for your child
- If necessary, explore how to receive access to your child's medical records
- If applicable, work with your child's provider to find a new adult provider that accepts your health insurance
- If it fits within your child's ability, encourage them to call their adult health care provider to schedule appointments and transfer their medical records so there is minimal lapse in health care services
- Learn if there are additional changes at 18 that may affect your child, including but not limited to: health insurance, Social Security Income

Age 22-25

- Encourage your child to continue receiving care from their adult provider, managing their health care, and updating their medical summary
- Keep track of your child's insurance status and update their provider if there are any changes in their health insurance coverage

TRANSITION TIMELINE

FOR PARENTS & CAREGIVERS OF YOUTH WITH MEDICAL COMPLEXITIES

Age 12-13

- Continue monitoring your child's health conditions, medications, and allergies
- Make a medical summary or care notebook with your child's provider or family navigator
- Start keeping a care notebook for your child

Age 14-15

- Plan for a medical emergency
- Create an IEP which discusses life after high school for your child
- Continue managing your child's appointments and referrals to specialists
- Prepare for your child's appointments by making a list of questions that you'd like to ask your child's provider

Age 16-17

- Be aware of when your child's medications need to be refilled and give adequate time for the provider and pharmacy to refill them
- If needed, invite Vocational Rehabilitation to IEP meetings to help plan for your child's transition after high school
- Make sure that your child's IEP includes plans for after high school, or if needed, supports for higher education or employment
- Explore options for substitute decision-making to support your child when they turn 18
- If applicable, add your child's name to the waiting list for residential placement

Age 18-21

- Consult Iowa Legal Aid or Disability Rights Iowa if you need help with substitute decision-making arrangements for your child
- If needed, explore options for accessing your child's medical records through medical power of attorney or guardianship
- If applicable, call your child's adult health care provider to schedule an appointment and transfer their medical records

Age 22-25

- Continue managing your child's health care and updating their medical summary
- Keep track of your child's insurance status and financial eligibility for social services
- Update your child's provider with any changes to their health insurance coverage
- If applicable, explore the possibility of your child with a disability staying on a parent's private health insurance plan

Note: If your child is not able to functionally participate in the transition process, it will be your ongoing responsibility to plan for your child's transition to the adult health care system



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.

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 in 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?



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 <i>Please check the answer that <u>best</u> 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

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 my medical needs. | <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"/> |
| I know what to do if I have a medical emergency. | <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"/> |
| I know what medicines I should not take. | <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"/> |
| I can name 2-3 people who can help with my health goals. | <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"/> |

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 doctor's phone number. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I make my own doctor appointments. | <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"/> |
| I have a way to get to my doctor's office. | <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"/> |
| I know where to get care when my doctor's office is closed. | <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"/>

Pediatric to Adult Care Transitions Tools

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 health 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? ☐ Yes ☐ No

Decision-making/Guardianship

- ☐ My youth can make my own health care choices.
- ☐ My youth needs some help with making health care choices (Name: _____ Consent: _____).
- ☐ My youth has a legal guardian (Name: _____).
- ☐ My youth/I need a referral to community services for legal help 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 adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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How confident do you feel about your youth's ability to prepare for and change to an adult doctor before 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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Your Youth's Health

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 his/her medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth can tell other people what his/her medical needs are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows what to do if he/she has a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows the medicines he/she takes and what they are for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth can take his/her medicine by himself/herself without a reminder.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows what medicines he/she should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows what he/she is allergic to, including medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth can name 2-3 people who can help him/her with his/her health goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My teen can explain to people how his/her beliefs affect his/her care choices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Pediatric to Adult Care Transitions Tools

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

DIFFERENCES IN CARE BETWEEN PEDIATRIC AND ADULT CARE

GUIDE FOR YOUTH AND FAMILIES

When you become an adult, your experience at the doctor's office and the hospital might be different from what you are used to. This fact sheet explains some of the changes you might notice.

Comfort & Familiarity		
Pediatric	Adult	Helpful Tips
<ul style="list-style-type: none">• You have known your providers for a long time• You feel comfortable during your visits• You know what to expect during the exam	<ul style="list-style-type: none">• You won't know much about your new providers and the staff• You will need to explain more about yourself and your condition• You might feel nervous about talking or meeting the provider• The exam might be different	<ul style="list-style-type: none">• Set up a "meet-the-provider" visit with your new providers• Be patient as your providers get to know you• Ask your pediatric provider to send records or a portable medical summary to your new adult provider• Tell the provider and someone you trust how you feel• Ask the provider to explain what will happen during the examination

Responsibility		
Pediatric	Adult	Helpful Tips
<ul style="list-style-type: none">• Parents/caregivers often stay with you during your provider visit• Parents/caregivers help answer questions from the provider for you• Parents/caregivers help make decisions about your treatment• Parents/caregivers arrange follow-up and check on test results• Parents/caregivers help you follow your treatment plan	<ul style="list-style-type: none">• You will decide if someone (friend, parent, caregiver) stays with you during your provider visits• You will explain things about your treatment and condition on your own• You will decide about treatment• You will follow-up on tests and appointments on your own• You will take more responsibility for your medical care	<ul style="list-style-type: none">• Don't be afraid to ask questions• Practice to be ready to take care of your own health• Ask your provider for help to build your skills• If you want, someone you trust can stay with you• Some may need help with adult expectations, and guardianship or alternatives may need to be explored

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

PARENTS & CAREGIVERS

Your child's teenage years is a great time to help teach them about their health issue, how to manage it, and how to properly take their medications.

You can support your child by:

- Helping them understand their health concerns
- Assisting them in taking medications
- Teaching them how to make their own appointments

Helpful Tips

- Take inventory of what your child currently knows about their health issue, medications, or allergies
- Help your child research their health conditions and discuss with them what information they find
- Assist your child in developing at least one question that they can ask their provider at their next appointment
- Help your child develop a system for tracking their medications and future appointments
- Provide your child with a copy of their health insurance card

Assess Your Child's 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 your child is ready to start the transition to adult health care. If applicable, share your results with your child and their health care provider.

Health Care Transition Quiz for Parents & Caregivers:

<https://gottransition.org/parents-caregivers/hct-quiz.cfm>

Got Transition Website: <https://gottransition.org/>

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
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--	--	--

Special Concerns for Disaster: _____

Allergies and Procedures to be Avoided

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

<input type="checkbox"/> Medications:	
---------------------------------------	--

Diagnoses and Current Problems

Problem	Details and Recommendations
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<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

Medications					
Medications	Dose	Frequency	Medications	Dose	Frequency

Health Care Providers				
Provider	Primary and Specialty	Clinic or Hospital	Phone	Fax

Prior Surgeries, Procedures, and Hospitalizations	
Date	
Date	
Date	
Date	
Date	

Baseline					
Baseline Vital Signs:	Ht	Wt	RR	HR	BP
Baseline Neurological Status:					

Most Recent Labs and Radiology		
Test	Date	Result
EEG		
EKG		
X-Ray		
C-Spine		
MRI/CT		
Other		
Other		

Equipment, Appliances, and Assistive Technology			
<input type="checkbox"/> Gastrostomy	<input type="checkbox"/> Adaptive Seating	<input type="checkbox"/> Wheelchair	
<input type="checkbox"/> Tracheostomy	<input type="checkbox"/> Communication Device	<input type="checkbox"/> Orthotics	
<input type="checkbox"/> Suctions	Monitors:	<input type="checkbox"/> Crutches	
<input type="checkbox"/> Nebulizer	<input type="checkbox"/> Apnea	<input type="checkbox"/> O2	<input type="checkbox"/> Walker
	<input type="checkbox"/> Cardiac	<input type="checkbox"/> Glucose	
<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

PARENTS & CAREGIVERS

As your child grows older, it's normal for them to want more freedom and privacy. Your child's health care provider may ask you if they can talk to your child alone, while you wait in another room. This lets the provider talk directly with your child and allows your child to talk about things they may not feel comfortable discussing in front of a parent.

To make sure the conversations between your child and their provider are private, youth are encouraged to make their own MyChart account. The only information a parent or caregiver can see is the child's immunization records. If you need access to access your child's medical records due to their health issue, CHSC staff will ask you to sign an Incapacitated Access form.

Decision-making is a skill that will take practice and experience for your child. Practicing this skill with your child now will help them make informed choices as they grow up.

Helpful Tips

- When your child turns 18, they will be in charge of their own health care decisions. They will be the only one who can view their health information.
- If your child desires to, they can ask their family or others to help them make health decisions or access their health information. To do this, the selected family members must sign a form to tell staff that they are allowed to be involved in a child's care.
- If your child needs more supports, some choices include:
 - Supported decision making
 - Health care power of attorney
 - Legal guardianship

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](http://www.NationalResourceCenterforSupportedDecision-Making.org) has information to connect you with resources in your state.

PLANNING FOR A HEALTH EMERGENCY

PARENTS & CAREGIVERS

Preparing for an 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 as a parent/caregiver to help prepare your child to act quickly and stay calm.

Helpful Tips

- Teach your child about the symptoms or signs that mean that they need to call 911 and how they are different from symptoms that can wait long enough for an appointment
- Use the Preplowans book to learn about how to make an emergency plan and build an emergency kit. Share this information with your child.
- If applicable, provide your child with a health alert bracelet or save an In Case of Emergency (ICE) contact on their cell phone
- Tell the police and fire department about your child's health issues so they know about their needs and how to help if there is a crisis
- Practice with your child how to tell others about their health issues and medications
- Encourage your child to always carry a form of ID and their insurance card

Helpful Resources

- Iowa's University Center for Excellence in Developmental Disabilities

Preplowans Book

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

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

PARENTS & CAREGIVERS

As your child grows up, you will not always be able to fill out your child's forms when going to their health care provider visits. It is important for your child to know their health history, your family's health history, and who can access their information.

Helpful Tips

- Teach your child that they will need the following documents to help make filling out health care forms less confusing:
 - Health insurance card
 - ID card
 - Shared Plan of Care (if they have one)
- Take some time to review with your child what might happen at their provider visit:
 - When they get to the clinic, a staff person will greet them and their family (if you are there with them). They may give your child the following forms (or others):
 - **Consent to Diagnose and Treat Form** – Gives staff permission to examine your child, make a diagnosis, and treat their health issue. Based on your child's age, you may be asked to sign this form, date it, and state what your relationship to the patient is.
 - **Registration and Health History** – Allows patient or caregiver to change their address, phone number, and insurance information, if needed. It will also ask the patient to list ALL of their health issues, medications, or allergies.
 - **HIPAA (Health Insurance Portability and Accountability Act) Form** – Lets patients decide who can see their health information. You may want to share health information with your insurance company, but it may be necessary to share this information with others in your child's circle as well. A parent/caregiver cannot access the health information of someone over age 18 unless they are named on the HIPAA form or legal arrangements have been made.
- A staff person may make a copy of your child's insurance card
- You (or your child) will be asked to fill out these health care forms while you wait for the provider. Make sure to read the forms carefully and write neatly. If there are questions or you need more time, let a staff person know.

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

PARENTS & CAREGIVERS

Staying healthy will allow for your child to have more freedom in making their own choices as they get older, as well as prevent other health issues from developing. Your child's self-esteem is important in how they feel and how they act. Teaching your child healthy habits can help increase their self-esteem and improve their quality of life.

Helpful Tips

- **Exercise**
 - Role model the importance of exercise to your child. Exercise helps your whole body – not just your physical health. It causes the body to make chemicals that help us feel good, sleep better, and lowers the risk of some health problems.
- **Substance Use**
 - As your child gets older, it will be up to them to decide whether to use alcohol, tobacco, and marijuana. Take some time to talk to your child about peer pressure, the health effects and risks of substance use, and what to do in a situation where they may feel uncomfortable.
- **Self-Esteem**
 - Teach your child about the concept of self-esteem. 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. Talk to your child about making positive choices about friends, relationships, and how to handle failure.
- **Nutrition**
 - Emphasize the importance of having a healthy and balanced diet. Teach your child to aim to eat at least five servings of fruits and vegetables each day.
- **Sexual Health**
 - Although potentially uncomfortable, don't hesitate in discussing with your child about what healthy, consensual relationships look like.
 - Your child will likely go through puberty as they transition from pediatric to adult health care. Prepare your child for the changes they might be experiencing, and how to develop healthy habits regarding self-care and personal hygiene.
- **Sleep**
 - Ensure that your child stays active during the day to aid in their sleep.
 - Encourage your child to avoid alcohol and drugs, as they might disrupt sleep and increase their chance of waking up in the middle of the night.
 - Set boundaries with your child regarding night-time electronic use.

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

PARENTS & CAREGIVERS

As your child gets older, they may need to start developing the skills needed to manage their own health care. While you may be there to help them, encouraging your child's independence by establishing small, achievable goals will help them gain the confidence needed to live more independently. Even though health care transition tends to focus on youth, it is sometimes the hardest for parents. As your child grows older, you may need to coach them into learning the skills necessary for health care management.

Why is this important?

- As your child gets older, it is normal for them to want more freedom and privacy. By establishing these health management skills, your child will be able to independently speak to their provider.
- No one knows your child's body than they do! Encourage your child to share their health concerns with their providers.
- If applicable, prepare your child for the appointment. You can role play with your child what might happen at the appointment, including:
 - Making an appointment, checking themselves in at the front desk, and speaking up during appointments.
 - The provider may ask to talk to your child alone. Communicate with your child that this is normal, and that they can share their concerns with the provider.
 - The appointment might be as short as 15 minutes. If applicable, encourage your child to write down their concerns so they can easily provide information.
 - At the end of visit, your child may need to check-out. This might include paying a co-pay, scheduling a future appointment, or completing additional paperwork.

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 your 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

The diagram shows a sample New York State Benefit Identification Card. The card is white with a purple border and features the New York State seal in the top right corner. The text on the card includes:

- 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
- ISO#:** 100123
- ACCESS NUMBER:** 1234 1234 123
- SEQ#:** 01
- Signature:** Sarah Jones

Labels on the left side point to the ID Number, Last Name, and First Name. Labels on the right side point to the Card Number, ISO Number, Access Number, and 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 _____ HIV-Related Information _____
_____ Mental Health 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

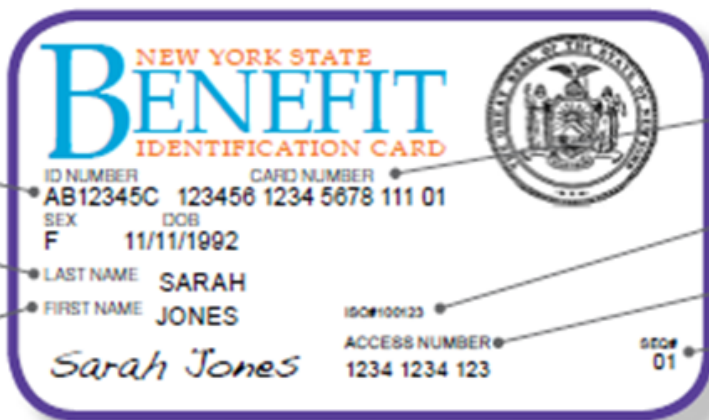
Number to call if there is a problem:

44-1234

Activities

Datatile

Contacts



ID Number

Last Name

First Name

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

PARENTS & CAREGIVERS

As your child gets older, they may need to learn skills to be able to get to medical appointments or other places around town. There may also come a time where you can no longer attend or physically take your child to their appointments, so helping them start to navigate transportation will be important for the future.

Helpful Tips:

- Brainstorm with your child about what methods of transportation they can use and have available to them. 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.
- Help your child use the internet or a phone book to find the address of the clinic and the best route to get there.
- Help your child practice how to get to the appointment ahead of time and keep track of how long it takes to them to get there.

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

PARENTS & CAREGIVERS

No one understands the effects that medications have on your child than themselves and their caregivers. Making sure that your child continues their medication regimen as they transition to adulthood will be important in helping them manage their symptoms. Helping your child gain the health care management skills of advocating for themselves when their medications are causing problems will also be an important component of transitioning to adulthood.

Helpful Tips:

- If applicable, help your child learn the names of their medications. Some medications have brand and generic names, so ask your child's provider if they can use the generic version.
- With the help of your child's provider, teach your child the reason for why they need to take their medication and how it treats their health issue.
- Encourage your child to tell their health care provider if they have any trouble taking their medication or if they experience side effects.
- Encourage your child to bring their prescriptions, over the counter medications, and supplements (if applicable) to their appointments.
- Help your child make a Medication List that includes:
 - Name of the medicine
 - How much they take (dose)
 - Time of day they take the medication
 - Why they take the medication
 - What happens if they skip the medication
 - Possible side effects or other medications that might impact the way their medicine works

For youth with medically complex needs:

- Share a medication list, dosage, and schedule with any person that may assist with your child's care. Your child may not be able to independently manage their medications, so ensuring that those around them are aware of their special needs will be important.
- Write down signs that your child may not be tolerating their medication well or signs that they are in pain. This will help those unfamiliar with your child in assisting them when needed.
- Write down what to do in an emergency and make sure to have your child's medical summary with them at all times. There may come a time when your child experiences a medical emergency and you are not with them. The medical summary will help providers best care for your child's needs.

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 Will Need:

- ☐ Cell phone
- ☐ Prescription bottle with label

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:

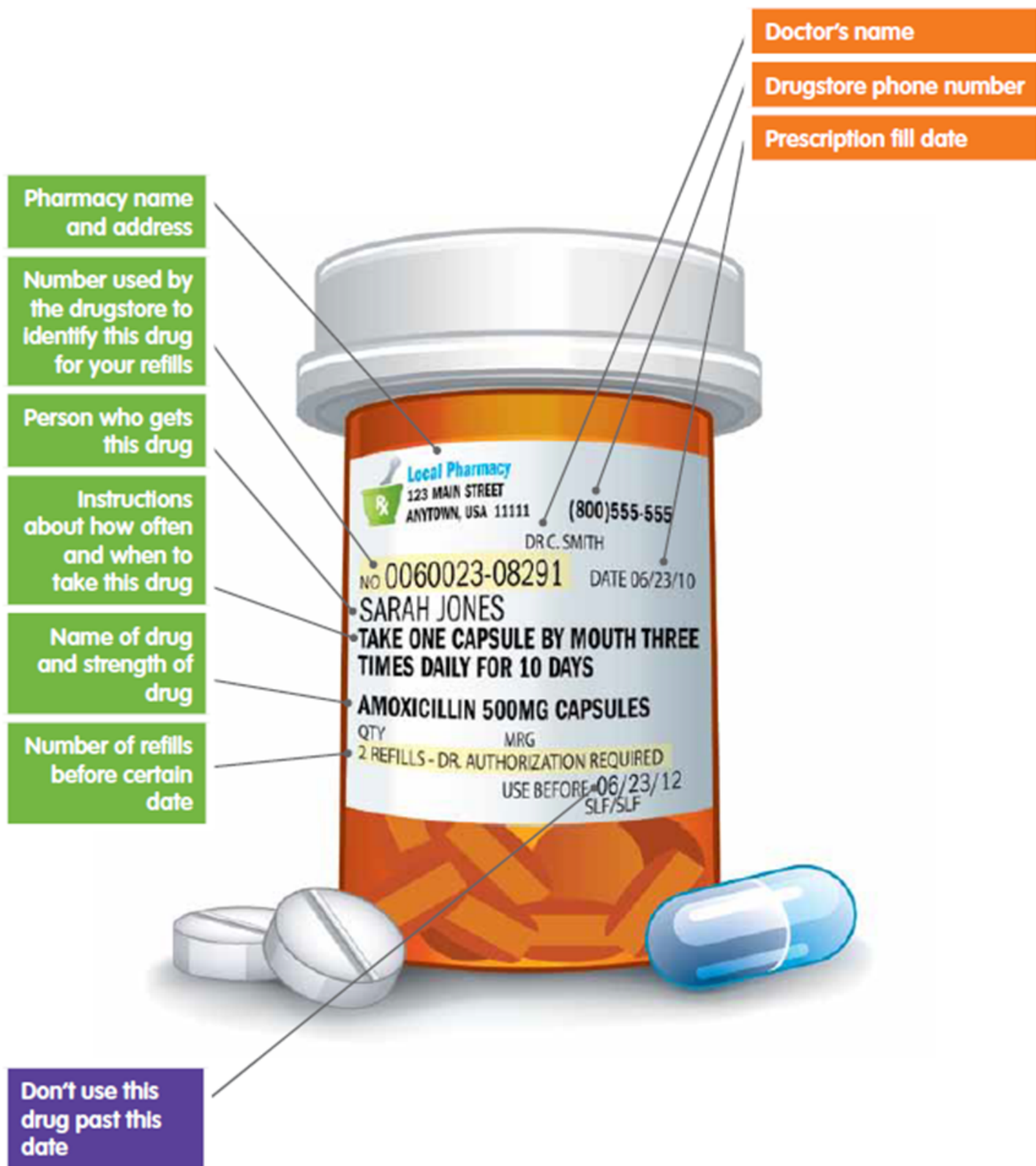
"Yes. I'd like to have the prescription delivered please"

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: _____.

Materials supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70MC12840. Developed by the UIC - Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics.



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

Materials supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70MC12840. Developed by the UIC - Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics.



UNDERSTANDING HEALTH INSURANCE

PARENTS & CAREGIVERS

Ensuring that your child has health insurance is a crucial component to the transition to adult health care. Health insurance pays for appointments, medications, hospital care, and special health equipment. Health insurance is also important when your child is NOT sick. Screenings, immunizations, and mental health care can help your child stay healthy as they age.

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, help your child understand their insurance coverage and what the terms mean.
- Start thinking about what insurance your child qualifies for when they turn 18. The type of insurance they get may greatly depend on their health care needs and the government programs they qualify for.
- Ask your child's 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 your child currently has Medicaid, they must reapply as an adult about 3 weeks before they turn 19.

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

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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.
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- 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

PARENTS & CAREGIVERS

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

Pediatricians are typically only trained to see patients until the age of 21, but some health issues that start when someone is a child may change as they get older. As they age, your child may also develop other health conditions that are more common in adults. If your child is seeing a family doctor now and you want to keep seeing them as an adult, you do NOT need to switch to a new PCP. If your child is currently seeing a pediatrician, your current pediatrician may help you find a new PCP that serves adults. This conversation typically happens around ages 17-21. Even if your child is seeing a family doctor, they may need to find new specialists that can better serve adults.

How to Find Adult Providers

- Ask your child's current provider for a referral
- Consider your own primary care provider as someone that could see your child
- Call your child's 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

PARENTS & CAREGIVERS (CONTINUED)

Questions to Ask

It is important to find a provider that makes your child feel comfortable and that can meet their unique needs. Before your child chooses 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 child's 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 child's specialists?
- Will the office be flexible to meet your child's health needs (allow service dog, schedule visits so you will not miss a meal, or schedule at quiet times if your child is sensitive to noise)?

Ask the Provider:

- Is the provider willing to discuss your child's health history and special needs with your child's pediatric provider?
- Does the provider currently see patients with health conditions similar to your child's?
- 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 child or are they constantly interrupting us?
- Can the provider explain information in a way that I or my child can understand?
- Does the provider take enough time to answer our questions?
- Does the provider treat my child and I with respect?

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
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FINDING ADULT HEALTH CARE PROVIDERS

YOUTH & YOUNG ADULTS (CONTINUED)

Questions to Ask

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- 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

PARENTS & CAREGIVERS

When your child turns 18, they are legally an adult. This shift happens regardless of whether your child can functionally participate in their health care. The provider will begin talking to your child, not the parents, about their health. The law that requires this is called HIPAA (Health Insurance Portability and Accessibility Act).

Helpful Tips:

- If your child wants to share their health information with you or others, the provider will need your child to fill out a form that grants you access to their medical record.
- If your child needs help making choices as an adult, discuss with your family, providers, or others you trust about who needs to be involved and how to best include them in your child's health care.
- 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.

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.
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Guardianship and Alternatives for Decision-Making Support

Written by: Got Transition Staff with support from Tina Campanella, Quality Trust for Individuals with Disabilities

HEALTH CARE TRANSITION AND DECISION-MAKING

For a youth or young adult who has intellectual disabilities, his or her health care transition often raises questions for health care providers and families about guardianship. This brief provides a high level look at guardianship and other decision-making supports as well as resources that will provide more in-depth information.

Guardianship Issues

Reaching the age of 18 — Opportunities and Challenges for Young Adults with Disabilities

Reaching the age of majority (18 years, in most states and jurisdictions) means, under state law, an individual is no longer a "minor." As such, the person has the right and responsibility to make certain legal choices that adults make. For some young adults with intellectual disabilities, this may be an exciting opportunity for increased independence. However, there may also be family concerns about how to best support that person's self-determination in making life decisions such as for health care or in financial management.

This brief provides a broad outline of decision-making support options, both informal and legal, that may assist a young adult with an intellectual disability. States and jurisdictions may have different laws and options. Each state defines the categories and rules for guardianship in its laws. It is important to know all of the options before deciding which one to pursue since every young person has a unique situation and individual needs for support.

Decision-Making — A Skill that Requires Practice and a Variety of Experiences

Decision-making is a learned skill. Children and youth who have support and experience choosing what to wear, eat, who to socialize with etc., will approach adulthood having exercised this skill early on. On-going decision-making experiences lead to confidence and a self-awareness that "I am able make decisions that direct my life." When a youth or young adult is denied the opportunity to make decisions or to participate in a shared decision-making process, this lack of skill building may lead to a perceived "incapacity" either by the family or by the young adult him/herself.

Despite having opportunities for decision-making early in life, not all young adults with intellectual disability are able to make all decisions especially those choices with more far reaching impact on their lives. In these situations, the right amount of support at the right time can help build on early decision making experiences.

The Right Support at the Right Time

"Informal" support from a young adult's circle of friends and family may be enough to help the young adult talk over life decisions while maintaining the young adult's unrestricted self-determination. When it comes to issues such as health care decisions or money management, there may be legal options available to assist the young person to "share" decision responsibilities with a trusted friend or family member. Joint or trust fund accounts, financial powers of attorney, health care durable powers of attorney, conservatorships or "waivers of confidentiality" for individual health care issues are options that can support a young person's decision making while providing timely guidance, as needed, for important issues.

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.

SOCIAL SERVICES FOR ADULTS

PARENTS & CAREGIVERS

Some of the programs that your child is enrolled in may end when they turn 18 or 21 years old. At that age, your child may qualify for programs that serve adults, but they must apply for them. Sometimes the things that allow your child to qualify for adult programs may be different from what allowed them to use programs as a child.

Helpful Tips:

- Ask your Family Navigator to help you make a list of the programs your child currently uses, when they end, and when to apply if there is a program for adults. They can help you figure out if your child qualifies for programs that serve adults and how to apply to them.
 - If your child does NOT qualify for a program, Family Navigators can help you think about other ways to meet your child's need as an adult. Examples may include Child Health Specialty Clinics services, Pediatric Integrated Health Home, Medicaid, Waivers, Vocational Rehabilitation, or Social Security Disability Insurance (SSDI).

[illegible]

SOCIAL SERVICES FOR ADULTS

YOUTH & YOUNG ADULTS

Some of the programs you are currently enrolled in may end when you turn 18 or 21 years old. At that age, you may qualify for programs that serve adults, but you must apply for them. Sometimes the things that allow you to qualify for adult programs may be different from what allowed you to use programs as a child.

Helpful Tips:

- Ask your Family Navigator to help you make a list of the programs you currently use, when they end, and when to apply if there is a program for adults. They can help you figure out if you qualify for programs that serve adults and how to apply to them.
 - If you do NOT qualify for a program, Family Navigators can help you think about other ways to meet your needs as an adult. Examples may include Child Health Specialty Clinics services, Pediatric Integrated Health Home, Medicaid, Waivers, Vocational Rehabilitation, or Social Security Disability Insurance (SSDI).

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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.	