



**Transition to Adult
Health Care Handbook**

For parents and young adults

Child Health Specialty Clinics

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Purpose of this Handbook



This **Transition to Adult Health Care Handbook**:

- Helps parents and caregivers support their children and youth with special health care needs as they transition to adult health care.
- Helps youth and young adults with special health care needs know their role and what supports are in place as they transition to adult health care

This handbook is not a full list of how to transition youth with special health care needs to the adult health care system. It is meant to be a guide for:

- Parents and caregivers
- Parents and caregivers of youth with other complex needs
- Youth and young adults

There are many organizations with excellent resources on the transition to adult health care. This handbook will provide direction to these external resources to help you or your youth in their transition.

Disclaimer: This handbook has legal and financial information and resources but does not give legal or financial advice.

Introduction to the Transition to Adult Health Care

For parents and caregivers

What is health care transition?

Health care transition means getting your youth ready for health care as an adult. When your youth was younger, you helped them by:

- Making doctor appointments
- Filling out medical forms
- Keeping track of their medicine
- Advocating on behalf of your child

As your child gets older, they may start doing some of these things on their own. While each child will gain various levels of independence as they enter adulthood, all youth will require an organized transition to adult health care to help them:

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

For children with special health care needs, turning 18 does not mean they can handle everything on their own. If your child has complex health needs, this handbook will give you tips and support to help you through the process.

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

We start talking about health care transition at age 12 so that youth and their families have time to get ready. The transition to adult health care can take time and be tricky, so starting early helps make things easier later.

Remember: You are not alone. There are health care providers and community supports to help you navigate the transition to adult health care.

Introduction to the Transition to Adult Health Care

For youth and young adults

What is health care transition?

Health care transition means getting ready for health care as an adult.

When you were younger, your parents or caregivers may have helped you with your health needs by:

- Making doctor appointments
- Filling out medical forms
- Keeping track of your medicines
- Advocating for you in health care settings

As you get older, you might need to start doing some of these things on your own. This might look like:

- Gaining independent health skills
- Getting ready for the adult health care system
- Finding adult health care providers that fit your needs

You may also find ways for your parents or caregivers to help you as you head into adulthood. There are resources in this handbook that will help you and your caregivers with these changes.

Remember: You are not alone. There are health care providers and community supports to help you navigate the transition to adult health care.

Transition to Adult Health Care Timeline: For Parents and Caregivers

- Check on your child's health, medicines, and allergies.
- Ask your child's provider when they no longer care for young adults.
- Find out when you will lose access to your child's medical record in MyChart.
- Work with your child's provider or family navigator to make a medical summary or care notebook.

- If your child is able, help them make their own appointments, ask questions, and refill medicine.
- Learn about your child's health privacy rights when they turn 18.
- Find out what may happen when your child turns 18, such as jobs, school, social services, and where to live.
- Learn how to help make decisions for your child when they turn 18.

- Encourage your child to keep getting care from their adult provider, keep track of their health care, and update their medical summary.
- Keep track of your child's insurance. Tell their provider if there are any changes in their coverage.

Age 12 to 13

Age 14 to 15

Age 16 to 17

Age 18 to 21

Age 22 to 25

- Talk what to do in a medical emergency.
- If your child is able, help them make their own appointments, keep track of medicine, and see their provider alone.
- Help with your child's appointments and referrals to specialists.
- Make a list of questions with your child to ask their provider.

- Set up any decision-making help.
- Learn how to access your child's medical records.
- Find a new adult provider who takes your child's insurance.
- Help your child schedule visits and transfer their medical records.
- Learn if there are any changes at 18 that may affect your child, like insurance and financial supports.

Transition to Adult Health Care Timeline: For Youth and Young Adults

- Learn about your health, medicine, 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.

- Make appointments, see your provider alone, ask questions, and refill your own medicine.
- Learn about your health privacy rights when you turn 18.
- Make a medical summary with your doctor or caregiver.
- Before you turn 18, find out if you need help making health care decisions.
- Start carrying your own health insurance card.

- Keep seeing your adult provider, take care of your health, and update your medical summary.
- Make sure you still have health insurance and tell your provider if anything changes.

Age 12 to 13

Age 14 to 15

Age 16 to 17

Age 18 to 21

Age 22 to 25

- Find out what you know about your health, health care, and medical history.
- Learn what to do in a medical emergency.
- Practice making appointments and ordering medicine refills.
- Start seeing your provider alone for part of the visit.

- You are a legal adult at age 18 and in charge of your health unless someone has been legally chosen to help make decisions for you.
- Find a new adult provider who takes your health insurance.
- Call your new adult provider to set up your first visit and move your medical records to them.

Note: This is a general timeline. Your personal timeline may look different.

Health Needs, Medicine, and Allergies

For parents and caregivers



Your child's teenage years are a great time to start teaching them about their health issue, how to manage it, and how to take their medicine.

You can support your child by:

- Helping them understand their health concerns.
- Helping them take their medicine.
- Teaching them how to make their own appointments.

Helpful tips

- Make a list of what your child knows about their health issue, medicines, and allergies.
- Help your child research their health conditions and talk with them about what information they find.
- Help your child write at least 1 question to ask their provider at their next visit.
- Help your child make a system for tracking their medicines and future visits.
- Give your child a copy of their health insurance card.

Check your child's readiness

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

Got Transition made a "Health Care Transition Quiz". Take this quiz to see if your child is ready to start the transition to adult health care. You can share the results with your child and their health care provider.

Quiz: gottransition.org/parents-caregivers/hct-quiz.cfm

Got Transition website: gottransition.org

Health Needs, Medicine, and Allergies

For youth and young adults



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

You can start taking care of your health needs by:

- Learning about your health issues.
- Knowing when to take your medicine.
- Learning how to make your own appointments.

Helpful tips:

- Think about what you know about your health issues, medicine, or allergies.
- Learn more about your health issues by researching it with your parent or caregiver. Talk about what you learned with your provider.
- Think of at least 1 question to ask your provider before your first visit.
- Use a pillbox or other system to keep track of when you take medicine.
- Use a calendar to keep track of visits and medicine refills.
- Keep a copy of your health insurance card with you. If you don't have a copy of your insurance card, ask your parent or caregiver for one.

Check your readiness

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

Got Transition made a "Health Care Transition Quiz". Take this quiz to see if you are ready to start the transition to adult health care. You can share your results with your parent or caregiver.

Quiz: gottransition.org/youth-and-young-adults/hct-quiz.cfm
Got Transition website: gottransition.org

Health Record Privacy

For parents and 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 speak with your child alone while you wait in another room. This lets the provider speak with your child about things they may not feel comfortable talking about in front of a parent.

To keep conversations between your child and their provider private, youth are encouraged to make their own MyChart account. The only information a parent or caregiver can see after a certain age is their child's vaccine records. If you need to see your child's medical records to help them with their health issue, 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 these skills with your child now will help them make informed choices as they grow up.

Helpful tips:

- Ask your provider when you will stop seeing your child's medical record. This is often around 12 to 14 years old. Look at your options and make a choice that is best for your family.
- When your child turns 18, they are in control of their health decisions. They will be the only ones who can see their health information.
- Speak with your child's provider about how to talk to them after your child turns 18. This can be important if you have safety concerns about your child.
- If your child wants to, they can ask their family or others to help them make health care decisions or see their health information. The chosen family members must sign a form telling staff that they can be part of your child's care.
- If your child needs more supports, some choices are:
 - Supported decision making, such as guardianship and conservatorship
 - Health care power of attorney
 - Legal guardianship

Health Record Privacy

For youth and young adults

As you grow older, it's normal to want more freedom and privacy. Your health care provider may ask to talk with you alone, while your parent or caregiver waits in another room. This lets your provider talk with you 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 or caregivers can see are your vaccine records. If your parent or caregiver needs to use MyChart because of your health issue, 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:

- Around age 12 to 14, you may need to start managing your own online medical record, such as MyChart. Talk to your caregivers and providers about how to best manage your online medical record. Ask for help if you need it.
- When you turn 18, you will be in control of your 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. You must sign a form to tell staff that these people can be part of your care.
- If you need more support, some options are:
 - Supported decision making
 - Health care power of attorney
 - Legal guardianship

Planning for a Health Emergency

For parents and caregivers



Getting ready for an emergency can be very important for people with special health care needs. Everyone has basic needs, like:

- Safe food, water, and shelter
- Going to the bathroom
- Bathing
- Communicating

Emergencies can be scary, but there are things you can do to get your child ready to act fast and stay calm.

Helpful tips:

- Teach your child when they should call 911 and when symptoms can wait until a doctor's visit.
- Learn how to make an emergency plan and build an emergency kit. Share this information with your child.
- If needed, give your child a health alert bracelet or save an In Case of Emergency (ICE) contact on their phone.
- Tell the police and fire department about your child's health issues so they know about their needs and how to help.
- Have your child practice how to tell others about their health issues and medicines.
- Encourage your child to always carry a form of ID and their insurance card.

Planning for a Health Emergency

For youth and young adults



Getting ready for a health emergency can be very important for people with special health care needs. Everyone has basic needs, like:

- Safe food, water, and shelter
- Going to the bathroom
- Bathing
- Communicating

Emergencies can be scary, but there are things you can do to get ready to act fast and stay calm.

Helpful tips:

- Talk to your parent or caregiver about what to do in an emergency.
- Learn when you should call 911 and when symptoms can wait until a doctor's visit.
- Learn how to make an emergency plan and build an emergency kit
- If needed, make sure you are always wearing your health alert bracelet and have an In Case of Emergency (ICE) contact on your phone.
- Tell the police and fire department about your health issues so they know how to help if there is an emergency.
- Practice how to tell others about your health issues and medicines.
- Always carry your ID and health insurance card with you.

Emergency Plan Worksheet

For young adults with special health care needs

Last updated: _____

Next review date: _____

About Me

Full name: _____

Birthday: _____

Nickname (what I liked to be called): _____

How I communicate: _____

My Health

Health concern(s): _____

Allergies: _____

Medical equipment I use: _____

Medicine

Name

Dose

When to take

Emergency Checklist

- Health insurance cards
- Medical summary
- Guardianship papers
- Emergency contact list
- Advance directives
- Medicine supply (3 to 7 days)
- Medical equipment and batteries
- Medical record copies
- ID card
- Comfort items
- Snacks and water
- Change of clothes

Special Care Instructions

Daily routine

Wake-up time: _____

Mealtimes: _____

Bedtime: _____



Calming techniques:

Mobility and positioning needs:

Feeding and nutrition information:

How I take my medicine:

Equipment set-up and back-up plan:

Sensory preferences:

Legal information:

Additional concerns:

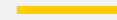
My health care providers:

Doctor: _____

Phone: _____

Specialist/therapist:

Pharmacy: _____



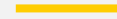
Emergency contacts:

Name: _____

Relationship: _____

Phone: _____

Back-up contact: _____



Emergency plans

Hospital: _____

Evacuation plan:

Shelter-in-place plan:

Who will help me in an emergency?

Filling out Health Care Forms

For parents and caregivers

As your child grows up, you will not always be able to fill out your child's forms at health care provider visits. Your child should know their health history, your family's health history, and who can access their information.

Helpful tips

- Teach your child that they will need these documents to fill out health care forms:
 - Health insurance card
 - ID card
 - Shared plan of care (if they have one)
- Go over what might happen at a provider visit with your child:
 - 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:
 - **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:** Lets patients or caregivers change their address, phone number, and insurance information (if needed). It will also ask the patient to list **all** their health issues, medicines, 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 and others in your child's circle. A parent or caregiver cannot see 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 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

For youth and young adults

As you get older, your parent or caregiver will not always be able to fill out forms at health care provider visits. You will need to know your health history, your family's health history, and who can see your health information.

Helpful tips:

- Make sure to have these documents with you when you go to your provider visits:
 - Health insurance card
 - ID card
 - Shared plan of care (if you have one)
- Go over what will happen when you go to a provider visit with your parent or caregiver:
 - 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. You or your parents 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** your health issues, medicines, or allergies.
 - **HIPAA (Health Insurance Portability and Accountability Act) form:** This form lets you decide who can see your health information. Ask the provider's office to share information with your insurance company and think of other people you might want to share this information with. A parent or caregiver cannot see 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

For parents and caregivers

Staying healthy lets your child have more freedom in making their own choices as they get older. Being healthy also prevents other health issues later on. Teaching healthy habits can help your child feel better about themselves and enjoy life more.

Helpful tips

- Exercise
 - Show your child that exercise is important. It helps your whole body, not just muscles. Exercise makes chemicals in the body that help us feel good, sleep better, and stay healthy.
- Substance use
 - As your child gets older, they'll make their own choices about things like alcohol, tobacco, and cannabis. Talk with them about peer pressure, how these substances affect their health, and what to do if they feel uncomfortable in a situation.
- Self-esteem
 - Help your child understand what self-esteem means. People with high self-esteem know themselves well, accept mistakes, and choose friends that value them for who they are. Talk to your child about making good choices about friends, relationships, and how to deal with failure.
- Nutrition
 - Teach your child to eat a balanced diet. A good goal is at least 5 servings of fruits and vegetables each day.
- Sexual health
 - Even if it feels awkward, talk with your child what healthy and consensual relationships look like.
 - As your child grows up, they'll go through changes like puberty. Help your child understand these changes, and how to take care of themselves with good hygiene and self-care habits.
- Sleep
 - Help your child stay active during the day so they can sleep better at night.
 - Talk about how alcohol and drugs can affect sleep and cause waking up in the middle of the night.
 - Set rules about using phones or other electronics at night.
- Healthy relationships
 - Teach your child about what good friendships and romantic relationships look like. Let them know they can talk to you if they have any concerns.

Making Healthy Choices

For youth and young adults

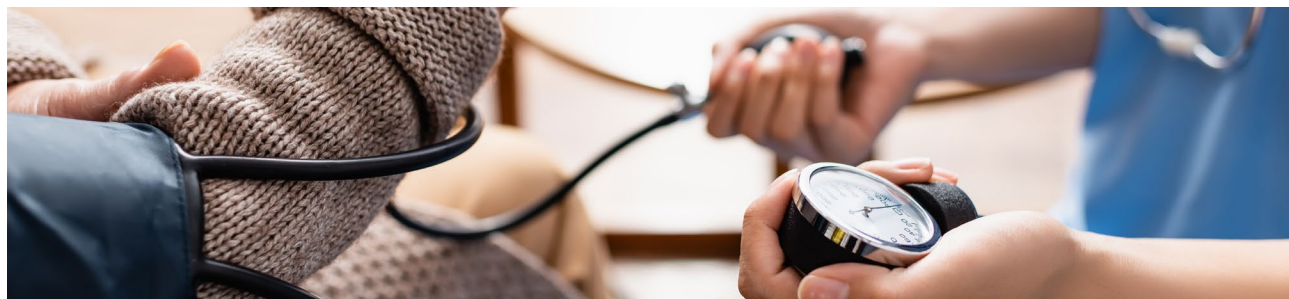
Staying healthy as you get older lets you have more freedom to make your own choices and prevents other health issues later on.

Helpful tips

- Exercise
 - Exercise helps your whole body. It makes chemicals in the body that help you feel good, sleep better, and stay healthy.
- Substance use
 - As you get older, you'll make your own choices about alcohol, tobacco, and cannabis. 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 ask your parent or caregiver to pick you up if you need help.
- Self-esteem
 - Self-esteem is 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 accept mistakes and choose 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 5 servings of fruit or vegetables each day. Try to eat a rainbow of colors to give your body the nutrients it needs.
- Sexual health
 - Even if it feels awkward, talk to your parent, caregiver, or other trusted adult about what a healthy and 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 hygiene looks like.
- Sleep
 - Stay active during the day so you can sleep better at night. Alcohol and drugs can affect sleep and make you wake up in the middle of the night.
 - Try not to use your phone or other electronics at night. This will turn your brain off and help you fall asleep faster.
- Healthy relationships
 - Talk to a trust adult about what healthy relationships look like. Make sure you can go to them if you have any concerns about your relationships.

Making Appointments, Checking In, and Talking with Providers

For parents and caregivers



As your child gets older, they start learning how to take care of their own health. You'll still be there to support them, but helping them set small, easy goals can build their confidence and help them become more independent. Even though health care transition mostly focuses on youth, it can be tough for parents too. You may need to guide your child as they learn how to handle their health care.

Why is this important?

- As your child gets older, it is normal for them to want more freedom and privacy. Learning how to manage their health helps them talk to providers on their own.
- Your child knows their body best. Encourage them to speak up about any health concerns.
- Help your child get ready for the visit. You can practice:
 - Making an appointment, checking in at the front desk, and speaking up during the visit.
 - The provider may ask to talk to your child alone. Let your child know this is normal and okay.
 - The visit might be as short as 15 minutes. If needed, help your child write down their concerns ahead of time.
 - At the end of the visit, your child may need to check out. This could mean paying a co-pay, making another appointment, or filling out paperwork.

Questions to ask your child before their next appointment:

- What health concern is most important to you right now?
- Why is this health concern important to you?
- What medicines are you taking? Are you having any side effects?
- Do you have any concerns about your medicine?
- Is there anything else you want to know or need help with?

Making Appointments, Checking In, and Talking with Providers

For youth and young adults



As you grow older, it's normal to want more freedom and privacy about your health and health care choices. You know your body best. Talk to your provider about your health concerns or they may not know something is wrong. Clinic staff will help you during your visit. Ask them questions if you do not understand something. The health care transition will be a change for you, but also for your caregiver(s).

Helpful tips

- Try new things, make mistakes, and learn from those mistakes.
- Your 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 to share any concerns you may have.
- Practice making an appointment, checking yourself in, and speaking up during the visit.
- The visit might only be 15 minutes. Write down what you want to tell your provider and make a list of your questions.
- At the end of the visit, you may need to check out. This could mean paying a co-pay or making another appointment. Try to practice these skills with an adult.

Questions to think about before your appointment:

- What is my main health concern right now?
- Why is this health concern important to me?
- What medicines do I take and how do they make me feel?
- Do I have concerns about my medicine?
- Is there anything else I want to know or need help with?

Transportation to Medical Appointments

For parents and caregivers



As your child gets older, they may need to learn how to get to medical visits or other places on their own. There might come a time when you can't go with them, so it's a good idea to help them learn about transportation now.

Helpful tips

- Talk with your child about different ways they can get around. Some choices are walking, riding a bike, scheduling a ride with their insurance company, taking a city bus, or driving themselves or with a trusted adult.
- Show your child how to look up the clinic's address online and figure out the best way to get there.
- Practice the trip before the actual appointment. Help your child keep track of how long it takes to them to get there.

Medicaid non-emergency medical transportation:

hhs.iowa.gov/medicaid/services-care/medical-transportation

Transportation to Medical Appointments

For youth and young adults



As you get older, you may need to learn how to get to medical visits or other places on your own. There might come a time when your parents or caregivers can't go with you, so it's important to learn about transportation now.

Helpful tips

- Brainstorm different ways you can get around. Some choices are walking, riding a bike, scheduling a ride with their insurance company, taking a city bus, or driving yourself or with a trusted adult.
- Look up the clinic's address online and the best way to get there.
- Practice the trip before the actual appointment. Keep track of how long it takes to get there.

Medicaid non-emergency medical transportation:

hhs.iowa.gov/medicaid/services-care/medical-transportation

Understanding Medicine and Getting Refills

For parents and caregivers

You and your child know best how their medicine affects them. As your child grows up, it's important to help them keep taking their medicine and learn how to speak up if something doesn't feel right. These skills will help them take care of their health as they become more independent.

Helpful tips

- If your child takes medicine, help them learn their names. Some medicines have a brand name and a generic name. Ask your child's provider if they can use the generic version.
- Teach your child why they need their medicine and how it treats their health issue.
- Encourage your child to tell their health care provider if they have trouble taking their medicine or if it causes side effects.
- Remind your child to bring all their medicines to appointments, including prescriptions, over-the-counter medicine, and vitamins or supplements.
 - Help your child fill out their Medicine Manager (see page 27).

For youth with medically complex needs:

- Share your child's medicine list, doses, and schedule with anyone that helps care for them. Your child may not be able to manage their medicine alone, so it's important others know what they need.
- Write down signs that your child might be in pain or not feeling well from their medicine. This will help others know when to step in.
- Write down what to do in an emergency. Always keep a copy of your child's medical summary with them. If something happens and you're not there, this helps your child's providers give the best care.

What to do if your child doesn't want to follow their health plan:

- Sometimes your child may not want to take their medicine or go to appointments. Here are some ways to help:
 - Talk with your child about their symptoms and what could happen if they don't take care of their health.
 - Ask open ended questions about why they don't want to manage their health care.
 - Stay calm and don't judge. Listen to what your child has to say.
 - Look for support, like a Family Navigator, who can help you understand and accept your child's choices, even if you don't agree.

Understanding Medicine and Getting Refills

For youth and young adults

You are the expert in knowing how medicine affect you. Keep taking your medicine and speak up if something doesn't feel right. These skills will help you take care of your health as you become more independent.

Helpful tips

- Have an adult help you learn the names of your medicines. Some medicines have a brand name and a generic name. Ask your provider if you can use the generic version.
- Learn why you need to take your medicine and how your medicine helps your health issue.
- Tell your health care provider if you have any trouble taking your medicine or if you have side effects.
- Bring all your medicine to appointments, including prescriptions, over-the-counter medicine, and vitamins or supplements.
 - Fill out the Medicine Manager handout (see page 27) to help you organize and understand your medicine.



Understanding Health Insurance

For parents and caregivers

Health insurance is very important as your child transitions to adult health care. Insurance helps pay for appointments, medicine, hospital care, and special medical equipment. It also helps when your child is not sick, such as for check-ups, immunizations, and mental health care.

Insurance definitions:

- **Co-insurance:** This is the part of the cost your child might have to pay for a health service. It is a percentage of the total cost and is paid along with the deductible.
- **Co-pay:** The amount you might have to pay for a covered service at the appointment.
- **Deductible:** The amount you must pay before insurance starts helping. For example, if your deductible is \$1,000, you must pay that much before insurance covers other costs.
- **Premium:** The amount paid every month (or every few months, or every year) to keep the insurance active. It might be paid by you, your employer, or the policyholder.
- **Network:** These are the clinics, doctors, and suppliers that work with your child's insurance. Ask your insurance which providers are in-network. Seeing someone outside the network might cost more.

Helpful tips

- If you can, help your child learn what their insurance covers and what the words mean.
- Start thinking about what insurance your child can get when they turn 18. The type of insurance depends on their health needs and what programs they qualify for. If you have private insurance, your child can stay on your plan until age 26.
- Ask your child's insurance company:
 - How much it costs to see a provider in-network and out-of-network.
 - How much your child's medicine will cost.
 - If there are limits on the number of visits for things like physical therapy or home health care, and if they need approval to see a specialist or go to the hospital.
- If your child has Medicaid, they must reapply as an adult about 3 weeks before they turn 19.

Understanding Health Insurance

For youth and young adults

Health insurance is very important as you transition to adult health care. Insurance helps pay for appointments, medicine, hospital care, and special medical equipment. It also helps when you are not sick, such as for check-ups, immunizations, and mental health care.

Insurance definitions:

- **Co-insurance:** This is the part of the cost you might have to pay for a health service. It is a percentage of the total cost and is paid along with the deductible.
- **Co-pay:** The amount you might have to pay for a covered service at the appointment.
- **Deductible:** The amount you must pay before insurance starts helping. For example, if your deductible is \$1,000, you must pay that much before insurance covers other costs.
- **Premium:** The amount paid every month (or every few months, or every year) to keep the insurance active. It might be paid by you, your employer, or the policyholder.
- **Network:** These are the clinics, doctors, and suppliers that work with your insurance. Ask your insurance which providers are in-network. Seeing someone outside the network might cost more.

Helpful tips

- Have your parent or caregiver teach you what your insurance covers and what the words mean.
- Start thinking about what insurance you can get when you turn 18. The type of insurance depends on your health care needs and what programs you qualify for. If you are covered by private health insurance, you may stay on the plan until you are 26.
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Health Insurance 101

Helpful tips to remember

Learning your insurance benefits

- Use providers that are in your network. This helps lower costs.
- Learn what your insurance covers. Look in your policy book to find your deductible and co-pay.
- Always carry your insurance card.
- Check if you need a referral from your primary care provider before seeing a new doctor or specialist.
- Ask if your insurance will pay to fix or replace medical equipment if needed.
- Read about how to appeal (ask for a review) if your insurance says “no” to a service you think should be covered.
- Before you turn 18 years old, find out when your current insurance ends and apply for adult insurance before your coverage ends.

Calling your insurance company

Be ready to share:

- Your name
 - Date of birth
 - Insurance ID number
 - Relationship to the policyholder (like self, child, parent)
 - Policyholder’s date of birth, address, and phone number
 - Date of service
 - Reason for the call
- A reference number, if you have one from a letter or email.

Keeping track of your insurance information

- Write down details from every phone call with the insurance company, like:
 - The date
 - The number you called
 - Who you talked to
 - What you talked about
 - What happens next
- Follow up to make sure problems get fixed.
- Keep all insurance papers in one place. This includes Explanation of Benefits forms, eligibility and denial letters, and notices about changes in covered or excluded services, deductibles, co-payments, or out-of-pocket costs.

Finding Adult Health Care Providers

For parents and caregivers

A **primary care provider (PCP)** is a provider who sees patients for regular check-ups, vaccines, and common health problems. They can also help your child find a specialist if needed. Seeing a PCP regularly helps catch health problems early.

Pediatricians often care for kids and teens up to age 21. If your child sees a pediatrician, they can help you find a new PCP who works with adults. This usually happens between ages 17 to 21.

If your child sees a family doctor, they can keep seeing that doctor as an adult. However, they might still need new specialists who treat adults.

How to find adult providers

- Ask your child's current provider for a referral
- Think about your own PCP as an option for 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
- Talk to your Care Coordinator or Case Manager
- Ask friends for suggestions

Questions to ask

It's important to find a provider who makes your child feel safe and respected. Before choosing, call the office and ask to speak with someone who can answer your questions, or make an appointment to meet the provider and staff.

Ask the office:

- Do they take your child's insurance?
- Are they taking new patients?
- Is the office easy to get to and move around in?
- What are the office hours? How can you reach them after hours? How do they work with your child's specialists?
- Can they meet your child's special needs (like allowing a service dog or scheduling quiet times)?

Ask the provider:

- Will they talk with your child's pediatrician about your child's health history and special needs?
- Do they see other patients with similar health needs?
- What hospital do they use for procedures?
- Where did they go to medical school? Are they board certified?
- Do they have special training or interests?

Ask yourself:

- Does the provider listen to me and my child?
- Do they explain things clearly?
- Do they take time to answer our questions?
- Do they treat me and my child with respect?



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Making the Most of Your Visit with Your Provider

For youth and young adults

When you were young, your parents or caregivers probably did most of the talking at your appointments. As you get older, it's important to start speaking up for yourself. It might feel hard at first, but it gets easier with practice.

Helpful tips

- Most appointments are only about 15 minutes long. If you think you'll need more time, ask the front desk to schedule a longer visit.
- Show up about 15 minutes early so you have time to check in.
- Ask your parent or caregiver to wait outside the room so you can talk to your provider alone.
 - This gives you a chance to talk about anything you want.
 - It also helps you get used to speaking for yourself.
- Before your visit, write down questions or things you want to tell your provider. It's easy to forget when you're there.
- Take notes during the visit or ask if you can use your phone to record what the provider says so you can remember later.
- Ask questions!
 - If you don't understand something, ask them to explain it again or in a different way.
 - Don't be afraid to ask, providers want to help you understand how to take care of yourself.

Making Decisions After Age 18

For parents and caregivers

When your child turns 18, they are legally an adult. This happens even if your child cannot functionally take part in their health care. Providers will talk directly to your child about their health, not to you. This is because of a law called HIPAA, which protects people's private health information.

Helpful tips

- If your child wants you (or someone else) to see their health records, they must fill out a form that gives permission.
- If your child needs help making health decisions, talk with your family, providers, or someone you trust to figure out who should help and how.
- There are different ways young adults can get help making decisions:
 - **Health care power of attorney:** Your child can choose an attorney to speak for them if they can't make health decisions on their own.
 - **Supported decision-making:** Your child can make a team of people they trust to help them understand their choices and make their own decisions.
 - **Guardianship and conservatorship:** These give someone else full control over health decisions that can only be changed by a court order. These options can be expensive and strict, so it's a good idea to look at all choices before deciding.

Guardianship and conservatorship in Iowa:

hhs.iowa.gov/medicaid/services-care/medical-transportation

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Social Services for Adults

For parents and caregivers

When your child turns 18 or 21, some of the programs they use might stop. At that age, they might be able to join programs made for adults, but they'll need to apply for them. The rules for adult programs can be different from the ones for children.

Helpful tips

- Ask your Family Navigator to help you make a list of:
 - The programs your child uses now
 - When those programs end
 - When and how to apply for adult programs
- If your child does **not** qualify for a program, Family Navigators can help you find other ways to support your child. Examples are:
 - Child Health Specialty Clinics services
 - Pediatric Integrated Health Home
 - Medicaid
 - Waivers
 - Vocational rehabilitation
 - Social Security disability insurance (SSDI)

Childhood program	Program end date	Adult program	When should I apply as an adult?	Did I apply yet?

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Transition to Adult Health Care Handbook

→ uihc.org/childrens/services/child-health-specialty-clinics