



MAINE  
PARENT  
FEDERATION

# Healthcare Transition

*A guide for parents and their young adults*





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# Transition to Adulthood

Transition to adulthood is a milestone... but it can often be a difficult time for young adults with disabilities because of changes to services and systems of care....

Therefore, it's important to help your young person plan ahead!

Develop self advocacy skills early. It is important for young people to understand their disability, communicate to others their strengths and challenges, and learn how to ask for what they need.



Create a transition plan for life after high school. Goals should include postsecondary education, employment and independent living. It also should include goals for independence with community activities, finances, relationships, and healthcare.



Provide opportunities and resources to help your young person understand their rights as an adult and encourage independence.

A **Person-Centered Planning (PCP)** approach ensure the young person is at the center of their life decisions.

A **Person-Centered Thinking** approach to transition plans, empowers the young person to be self-determined across all areas of their life.

Maine has adopted eight Life Domains to promote PCP conversations.

One of the eight life domains is **the Health & Wellness Domain** providing guidance and help ensure access and management of a person's own healthcare.

[PCP Guide Life Domain - Health Wellness.pdf](#)

For more information on PCP and all eight domains visit:

[Person-Centered Planning | Department of Health and Human Services](#)

# Health & Wellness Domain

## Healthcare transition involves

- 1) managing your own healthcare
- 2) living a healthy lifestyle
- 3) knowing your medical rights  
*ex. privacy and confidentiality*

## Healthcare/wellness includes

- medical /dental /vision health
- mental health/behavioral health
- developmental stages & changes
- holistic wellness - nutrition and exercise/activity

# What is Healthcare Transition

**Healthcare Transition is the process of moving from a pediatric to an adult model of healthcare.**

It is a complex system that often requires assessment, planning and self advocacy. It is important to prepare a young adult for this transition.

Teach

- Teach a young person about their individual healthcare needs, services, and providers

Shift

- Shift responsibility from the parent to the young person to develop independence

Talk

- Talk to the young person about their healthcare/wellness goals

Practice

- Practice supported decision making with your young adult

# In Healthcare..... every individual has the right to make decisions

1

When young people with disabilities reaches the “age of majority,” or 18 years of age, they gain the right to manage their own affairs, including choosing their own doctor and managing their own healthcare needs.

2

Even when families have a guardianship arrangement in place, a parent or guardian still needs to ask the young adult for their opinion and allow them some say in their healthcare decisions.

3

Providing opportunities for your young person to talk to medical professionals and practice making decisions about his or her own healthcare with support from a caregiver is a great starting point.

4

Opportunities to Practice Supported Decision Making is one way of doing this. Build a natural support team around your young adult to provide education, resources and support. Allow the young adult to make the final decision.

5

It is important to know that Releases of Information must be signed if a young adult would like their parent, caregiver or anyone else to support them during appointments or to allow health information to be shared with them.

# Americans with Disabilities Act

The ADA is a law that protects people with disabilities and ensures that they are able to participate in all aspects of public life and receive equal opportunities.

The ADA prevents discrimination and provides accommodations throughout their life.

In healthcare - public entities must modify their practices to ensure people with disabilities are not denied the ability to participate and benefit from goods and services. Public entities must adjust and provide reasonable accommodations.

Healthcare examples include:

- aid with completing paperwork & help with the registration process
- provide a quiet space to wait or make specific appt times
- use plain language or visuals to help explain what is being discussed
- provide longer appts to allow providers extra time to explain recommendations
- modify equipment being used and have an accessible office space
- Provide communication aids and also ensuring privacy

# Health Information Portability & Accountability Act

HIPAA is a federal law that focuses on privacy & security of health information.

HIPAA ensures accessibility and confidentiality of communication related to healthcare information. It provides appropriate accommodations and ensures safeguards when transmitting personal health information to accommodate the specific needs of patients with disabilities.



**This means individuals private health information is safe and protected.**



**This means individuals are allowed privacy in appointments and procedures.**

- Remember to have releases signed if the young person wants to have someone support them in an appointment.
- A young adult should be the one talking with healthcare providers during their appointment. Providers should speak directly to the individual about their healthcare concerns and goals.
- Make sure the provider understands the young person's needs and that a plan is in place allowing them to fully participate in the appointment.
- An Advance Care Directive should be completed with the young adult and kept on file as a safety net.

# How do we start

Adults can make our own choices about our healthcare. We get to choose who we want to provide our health care and what our healthcare goals are.

Parents can begin by providing their young person with information about their current healthcare system; such as the services they receive, the providers they see, and how they assess their individual health needs.

Questions to discuss with them

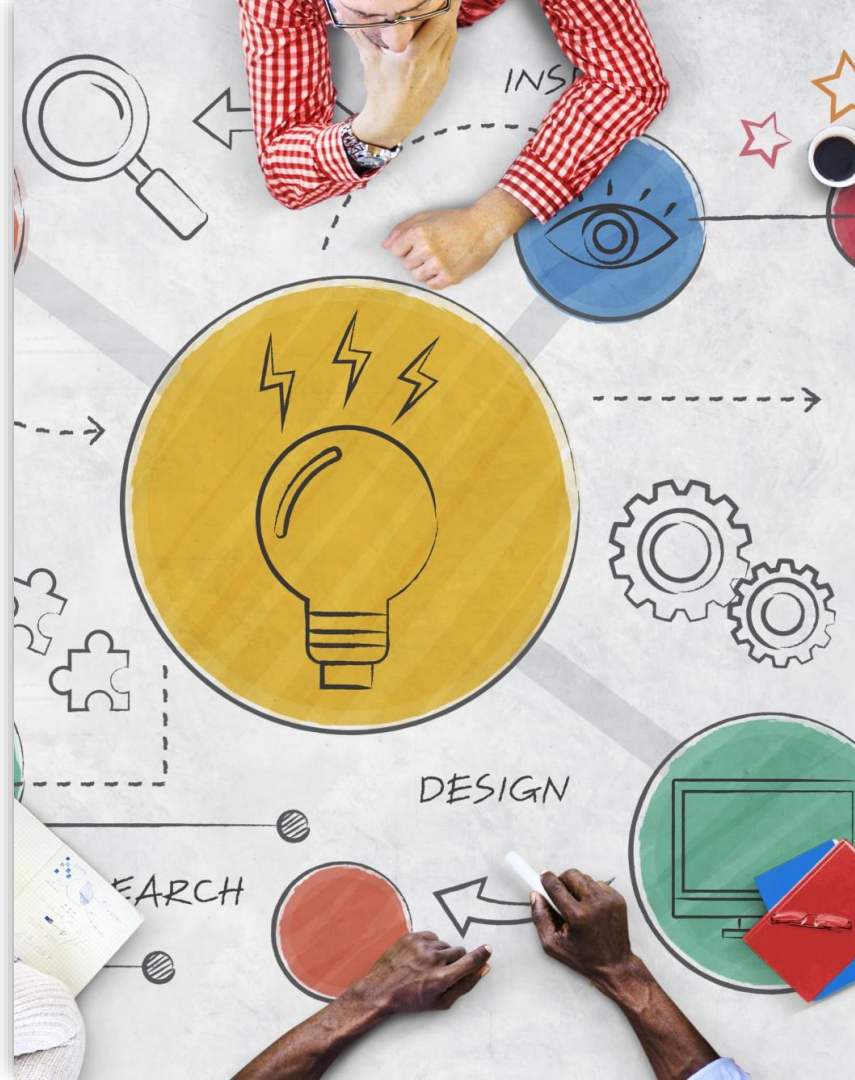
- What do you like about your doctors?
- What don't you like about your doctors?
- What is working with your health care now?
- What could be better?



# Transition Assessment tools

A young person and their caregivers can begin by assessing the persons' current needs and also begin thinking about future needs.

- [Sample Transition Readiness Assessment for Youth](#)
- [Sample Transition Readiness Assessment for Parents/Caregivers](#)



# Some first steps for the young adult.....

A young adult can begin learning by asking their parent/caregiver questions about their current healthcare needs and system of care. Parents may have to initiate these conversations to begin the shift of responsibility. Keep the information in a safe place, so the young person can find it again. Questions that a young person can ask;

- What is my medical history and diagnosis, including allergies?
- Who are my healthcare providers What is their contact information? - medical, dental, vision and mental health?
- Where else do I receive care? Make a list of the addresses and phone numbers for healthcare facilities, clinics, & hospitals.
- How do I make an appt? Can I have a calendar to keep track of appts?
- What medications do I take and what pharmacy do I use? How do I get refills?
- What is my Insurance plan? What does it cover, and how do I access it?
- How do I access my personal health information? Do I have an online portal and log in?

*Begin with small tasks and give more responsibility as you go. Provide your young adult with support and allow them to communicate with their providers during appointments, while completing paperwork, and when scheduling appts.*

# Young adult participation in healthcare appts

- **Talk about your disability and what you need**
- **Bring a list of medications and allergies**
- **Bring a list of questions you have**
- **Bring a list of concerns/problems/specific description of symptoms**
- **Ask for clarification if you don't understand**
- **Ask for a written summary of your appointment or a transcript**
- **Understand the types of appts - routine/preventative vs. acute appt - illness or injury**
- **During exams and procedures -Providers should explain what is happening before an individual signs a consent form. The individual should understand the benefits as well as the risks or complications involved and should be made aware of alternatives to a procedure.**

*\* An individual can always sign a release if they want someone else in the appt to help support them*

# Managing Medications



MEDICATION LIST



DOSAGE



SCHEDULE



SIDE EFFECTS TO  
BE AWARE OF



REFILLS



REMINDERS

Healthcare  
Transition  
also  
includes

Routine preventative healthcare

Know what you need and when

Understand changes in your body

Determine future needs

Navigate relationships/sex/reproduction

Have emergency plans in place

# Understanding Insurance Coverage

INSURANCE

COPY OF CARD

WHO TO CALL

WHAT  
SERVICES ARE  
COVERED

WHAT DO YOU  
PAY FOR

# Healthcare Insurance Coverage

Understanding health insurance coverage and how to access it is an important part of managing one's healthcare. Make sure your young adult has the following information and it is stored in a safe place for future access:

- Health insurance plan name & phone numbers
- Copy of the plan coverage
- An explanation of out-of-pocket expenses (copays & coinsurance)
- Copy of insurance card

## Possible healthcare insurance options as a young adult:

- MaineCare is Maine's Medicaid program and provides health insurance coverage for some individuals with disabilities.
- Private Health Insurance provided by a parent's health insurance plan may be an option for some young adults until they turn 26 years of age.
- Private health insurance provided by the young adult's employer may also be an option for employed young adults.

# It is important to begin talking early, questions to begin the conversation ...

Do you wear a medical alert bracelet or necklace?

- Does it list your allergies and/or conditions?

Do you speak up for yourself during medical appointments?

Do you help make your healthcare decisions with your doctor?

Do you see your doctor without your parent/caregiver in the room?

Do you know how to describe your disability & how it impacts daily life?

Do you know how to maintain a healthy lifestyle?

Do you know how drugs, smoking/vaping, & alcohol will impact your condition (or react with medications)?

# Planning for the future starts with conversations....

Do you know your rights to keep your medical information private (HIPAA)?

Do you call your doctors on your own if you have a medical problem?

Do you know how to schedule your own medical appointments?

Do you know the names of your medications, why you take them, & side effects?

Do you know what can happen if you skip treatments & medications?

# Adult questions to consider and plan for...

Do you know what you'll do for birth control, safe sex, & reproductive concerns?

Do you almost always take your medication correctly on your own?

Do you know how to use your health insurance benefits (co-pays, referrals)?

Do you know when & how to fill your prescriptions (knowing who prescribed them, where to call & how to get refills on time)?

Do you use and take care of your own medical equipment and supplies?

Do you know when to call for routine checkups? Do you know when to seek urgent care or when to go to the emergency room or call 9-1-1?

# Sexual/Reproductive Healthcare

**As an adult, sexual/reproductive health is another area of life in which important decisions need to be made. Having conversations and ensuring your young adult has access to medical providers that specialize in this area is very important. Consider and discuss the questions below with them:**

- Is your young adult in a romantic relationship or are they interested in one?
- Do they understand how their disability impacts connection/closeness?
- Do they have someone safe to talk to about their feelings, relationships and sexual desires?
- Do they desire and understand intimacy?
- If they decide to be sexual, do they know how to protect themselves against STI's and pregnancy?
- How do their personal values or goals affect their decisions? Consider and discuss fears also.
- Do they know where to go for care, including providers and clinics?
- Do they have safety plans in place to protect themselves?

\*These conversations can often be difficult, but preparing your young adult and providing a safe place for talking through these considerations will help them make better decisions.

# Parents play a key role

Ensuring that our young adults have information about their individual healthcare needs, are connected to the needed resources, have the tools to self advocate and have the supports in place will help ensure a smoother healthcare transition.

Developing self advocacy skills early and practicing supported decision making is an important place to start.

Start conversations now. What does your young adult still need to learn about their overall health and wellness?

Building independence and responsibility. How are they independent now? How can you expand on that?

Does your young adult talk about their disability and do they understand their rights? Provide the education.

Complete an advance care directive with your young adult and get releases signed if needed.

# Resources



[Health Care Transition –  
LifeCourse Nexus](#)



[ASAN-healthcare-toolkit-  
final.pdf](#)



[Home - Health Care for  
Adults with Intellectual  
and Developmental  
Disabilities](#)



[GETTING THE CARE YOU  
NEED](#)

# Who can Help

**Office of Aging and Disability Services (OADS)** supports Maine's disabled adults by providing Adult Protective, Brain Injury, & Other Related Conditions, Intellectual Developmental Disability, Long-Term Care, & Aging & Community services to the people of Maine. <https://www.maine.gov/dhhs/oads>

**Home and Community Based Services (HCBS)** provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. If you meet eligibility criteria and meet the medical and financial requirements of a Home and Community-Based Waiver program then you may qualify to receive services through one of our Home and Community Based Services waiver programs. Visit the [Office of Aging and Disability Services webpage](#) or the [MaineCare Member Handbook \(PDF\)](#) for more detail about waivers.

**MaineCare Waivers Sections** for Adults include:

**Section 18** - Brain Injury Waiver Services

**Section 19** - Elderly and Adults with Disabilities Waiver Services

**Section 20** - Cerebral Palsy, Epilepsy and Seizure Disorders Waiver Services

**Sections 21 & 29** - Intellectual Disabilities and or Autism Waiver Services

<http://www.maine.gov/sos/cec/rules/10/ch101.html>



## Family Support Navigators

Our Family Support Navigators are trained parents who have personal experience navigating the systems of care in Maine and can provide support at no-cost to you!



# MAINE PARENT FEDERATION

Please stay connected!

526 Western Ave, #2  
Augusta, ME 04330

[www.mpf.org](http://www.mpf.org)

