

# Healthcare Transition

**Best Practices for Families/Caregivers**



# Contents

## Early Transition Skills (developmental ages 12 -14)

- Health & Wellness
- Access & Recreation
- Navigating Insurance & State Programs
- Questions to Consider

## Middle Transition Skills (developmental ages 15 -17)

- Health & Wellness
- Access & Recreation
- Navigating Insurance & State Programs
- Questions to Consider

## Late Transition Skills (developmental ages 18+)

- Health & Wellness
- Access & Recreation
- Navigating Insurance & State Programs
- Questions to Consider



All youth/young adults must "graduate" from their pediatrician to an adult medical provider. This transition is especially challenging for the disabled community. The American Academy of Pediatricians acknowledges that medical transition has not been established with providers.

This booklet provides best practices for families to ensure proper medical care throughout a lifetime.

## Early Transition Skills 12-14

# Health & Wellness



## Best Practices for Parents/Caregivers

1. Direct the physician to speak directly to & meet alone with the youth/young adult.
2. Schedule appointments with the youth/young adult & add to their calendar.
3. Educate self about medical rights to privacy (HIPAA).
4. Educate the youth/young adult on their disability and the impact it may have on their daily activities. Teaching them to advocate for their needs.
5. Educate the youth/young adult on medications - dosage, interactions/allergies, & when to take them.
6. Consider releases with other providers (schools) for strong communication about needs.

## **Early Transition Skills 12-14**

### **Access & Recreation**



## **Best Practices for Parents/Caregivers**

1. Encourage youth/young adult to participate & volunteer in extracurricular & community activities.
2. Educate on proper use of social media & it's impacts.
3. Encourage youth/young adult to engage in age-appropriate peer relationships & supports.
4. Educate youth/young adult about Special Education Law to access school activities with appropriate accommodations.
5. Educate youth/young adult on diet, exercise, mental health, dental health, drugs/alcohol, smoking/vaping, safety (seat belts etc.), sexuality, & how they may impact their disability.

## Early Transition Skills 12-14

# Navigating Insurance & State Programs



## Best Practices for Parents/Caregivers

1. Parent education on healthcare insurance including MaineCare & Katie Beckett and any age limits.
2. Educate youth/young adult about how to locate insurance card(s) & what copays may be.
3. Encourage youth/young adult leading check in & out of appointments, picks up prescriptions, & has knowledge of related copays.
4. Parent education on Children's Case Management and how they can assist in preparation for transition to Adult Services.



## **Early Transition Skills 12-14**

# **Questions to Consider with Youth/Young Adult**

- 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 (react with medications)?



## **Middle Transition Skills 15-17**

### **Health & Wellness**



## **Best Practices for Parents/Caregivers**

1. Provide opportunities for youth/young adult to make their own medical decisions with providers.
2. Practice with youth/young adult to name & contact primary physician & make their own appointments.
3. Inquire on office policies on transition.
4. Practice, under caregiver supervision, youth/young adult to become responsible for taking & ordering medications.
5. Educate youth/young adult on sexuality, reproductive health including STD's, self-exams, birth control, & healthy relationships.
6. Educate youth/young adult on mental health (depression, anxiety, self-harm, pain/discomfort, & bullying)



## **Middle Transition Skills 15-17**

### **Access & Recreation**



## **Best Practices for Parents/Caregivers**

1. Investigate driver education options (Alpha 1)/public transportation options.
2. Educate youth/young adult on proper use of social media & its impacts.
3. Assist in identifying natural supports (friends, family, community).
4. Encourage youth/young adult to independently practice self-care (dressing, hygiene, laundry, & food preparation etc.).
5. Encourage youth/young adult to practice & explore money management, independent living arrangements, employment, & post-secondary education after high school.

## **Middle Transition Skills 15-17**

# **Navigating Insurance & State Programs**



## **Best Practices for Parents/Caregivers**

1. Practice with youth/young adult to use health insurance (co-pays & referrals).
2. Engage in family conversation and decide what healthcare and support services are needed for adulthood. For example, private health insurance, MaineCare, SSI/SSDI & Waiver Services
3. Engage in family conversation about guardianship, supported decision-making & implications of age of majority.
4. Educate self on eligibility for Vocational Rehabilitation (VR) & Adults Services through the Office of Aging & Disability Services (OADS) Sections 19, 21 & 29 (2025 LifeSpan Waiver).



## **Middle Transition Skills 15-17**

### **Questions to Consider with young adult**

- Do you know your rights to keep your medical information private (HIPPA)?
- 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?
- Do you know how your condition effects sexuality (the need for closeness, caring, & touching)?

## **Middle Transition Skills 15-17**

### **Additional Questions to Consider**



- Do you know what you'll do for birth control, safe sex, & reproductive concerns?
- Do you have a plan for health insurance when you are an adult?
- Do you know how to use your health insurance benefits (co-pays, referrals)?
- Do you know what you will do after high school (job, more school, recreational options, volunteer etc.)?
- Do you know resources to connect with adult services (job support, transportation, assistive technology etc.)?
- Do you know how your condition may impact
  - job choices? sexuality (the need for closeness, caring, & touching)?

## **Late Transition Skills 18+**

### **Health and Wellness**



## **Best Practices for Parents/Caregivers**

Youth/young adult:

1. Makes appointments & accesses medical history.
2. Orders prescriptions, understands dosage & reason for medication, & the possible side effects.
3. Knows emergency contacts & how to reach them.
4. Understands sexuality & reproductive health including STD's, self-exams, birth control, & healthy relationships (domestic violence) & who can support them with these topics.
5. Understands mental health (depression, anxiety, self-harm, pain/discomfort, & bullying) & who can support them with these topics.

**Late Transition Skills 18+**

## **Access and Recreation**



### **Best Practices for Parents/Caregivers**

Youth/young adult:

1. Knows transportation options & how to access them, including a driver's license (Alpha 1).
2. Understands how to access social media & it's impacts.
3. Has a supported decision-making plan with natural supports regardless of guardianship arrangements.
4. Understands legal arrangements in place for decision-making arrangements (guardianship, releases, advanced medical directives, & power of attorney).
5. Is able to either independently do self-care money management, living arrangements, post-secondary education, employment, & leisure or can identify the areas of need & know who to contact for assistance.

**Late Transition Skills 18+**

## **Navigating Insurance & State Programs**



### **Best Practices for Parents/Caregivers**

Youth/young adult:

1. Has access to private (parent/caregiver insurance up to age 26) and/or MaineCare insurance.
2. Has access, if appropriate, to adult SSI/SSDI.
3. Registers to vote and if a male selective service (military) if eligible.
4. Has access, if eligible, to Vocational Rehabilitation (VR) & Adults Services through the Office of Aging & Disability Services (OADS) Sections 19, 21 & 29 (2025 LifeSpan Waiver).
5. Understands post-secondary education options including public school through age 22, adult education, & apprenticeships.





## **Late Transition Skills 18+** **Questions to Consider** **with young adult**

- Do you have an updated portable medical summary or plan?
- Do you have a doctor who treats adult patients?
- Do you almost always take your medication correctly on your own?
- Do you know when & how to fill your prescriptions (knowing who prescribed, where to call & getting 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?

## **Late Transition Skills 18 +**

# **Additional Questions to Consider**



- Do you know who to call about questions about your insurance plan?
- Do you know how you will maintain health insurance as an adult?
- Do you know what government benefits you may qualify for (SSI/SSDI, Health Benefits for Workers with Disabilities, & Home & Community Based Services etc.)?
- Do you know about supported decision-making, guardianship, & power of attorney?
- Do you know about your options for housing as an adult (on your own, group home)?
- Do you know how to manage your money and pay your bills?

# RESOURCES

Maine Parent Federation - Information, referrals, peer-to-peer support, warmline, & training to families of children with disabilities.

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

Autism Society of Maine - Education, advocacy, support, & public awareness to promote access and opportunity for all individuals on the spectrum.

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

G.E.A.R. Parent Network - Empowering families of children with behavioral health needs to build their strengths and advocate for their needs.

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

# RESOURCES

Maine Medical Center Benefits Counseling - Statewide counseling on the use of social security benefits.

Available only to those currently receiving benefits.

<https://mainehealth.org/maine-medical-center/services/vocational-services/benefits-counseling>

Maine Families - Washington County only. Resources and information to help families of special needs children navigate systems of care.

<https://mainefamilieswc.org/community-resources/child-adult-special-needs/>

2-1-1 - Connects families to health, financial, and educational services.

<https://211maine.org>

# RESOURCES

Maine Katie Beckett Program - MaineCare option for children with disabilities under 18 to receive full benefits under MaineCare.

[www.maine.gov/dhhs/oms/mainecare-options/children](http://www.maine.gov/dhhs/oms/mainecare-options/children)

NAMI Maine - Support, education & advocacy for families, individuals, & professionals impacted by mental illness.

<https://namimaine.org>

Maine Department of Vocational Rehabilitation - Pre-Employment Transition Services & Employment Services to eligible students with disabilities.

[http://www.maine.gov/rehab/dvr/youth\\_transtion.html](http://www.maine.gov/rehab/dvr/youth_transtion.html)

# RESOURCES

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>

Maine Waivers Section 19, 21, & 29 - Eligibility requirements;

1. Be 18 or older.
2. Have a case management agency.
3. Meet medical & financial requirements.
4. Have an intellectual disability or autism.

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



# RESOURCES

## MaineCITE -

The Maine Department of Education's Maine CITE Program is designed to help make assistive technology more available to Maine children, adults and seniors who need them.

<https://mainecite.org>

## Brain Injury Association of America- Maine -

The Brain Injury Association of America – Maine Chapter (BIAA-ME) works to increase awareness of brain injury, provide information, resources, and support for individuals who have sustained brain injuries and their families, and advocate for prevention and improved funding and services across the state of Maine.

<https://www.biausa.org/find-bia/maine>