

# Issues in Transition from Pediatric to Adult Health Care for Youth with Epilepsy



Craig M. Schramm, M.D.

Chief, Pediatric Pulmonary Division

Connecticut Children's Medical Center

Associate Professor of Pediatrics

University of Connecticut Health Center



# Objectives:

1. Understand the difference between health care transition and transfer, and recognize the rationale for transition.
2. Name barriers to successful health care transition.
3. Describe self-care skills essential to health care transition.
4. Know state legal and insurance issues pertinent to health care transition.
5. Identify resources to assist with health care transition.

# Terminology:

## Transition



**Transfer:** a simple **event** characterized by the movement to a new health care setting , provider, or both.

# Terminology:

**Transition:** a planned **longitudinal education process** that provides comprehensive, developmentally appropriate health care in a coordinated and uninterrupted manner.



**Transfer:** an **event** characterized by the movement to a new health care setting , provider, or both.

# Terminology:

Transition is a complex, multidimensional process in which the individual gradually moves from a child being cared for...



...to an independent and autonomous young adult with his or her own responsibilities

# Terminology:

Transition is a complex, multidimensional process in which the individual gradually moves from a child being cared for...



Goal is to help children become adults who are as independent as possible and who have the best seizure control as possible.



...to an independent and autonomous young adult with his or her own responsibilities

# Scope of the Problem:

- Epilepsy is the most common childhood-onset neurological disorder continuing into adolescence, affecting 15 million children globally.
- It is a disorder characterized not only by seizures but sometimes also by behavioral, social, physical, and intellectual disabilities.
- Seizures remit in about 50% of patients during childhood but persist into adulthood in the other 50%.

# A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs

- American Academy of Pediatrics
- American Academy of Family Physicians
- American College of Physicians
- American Society of Internal Medicine



# Rationale:

A well-timed transition from child-oriented to adult-oriented health care allows young people to optimize their ability to assume adult roles and functions.

- Children receive optimal primary care in a medical practice experienced in the care of children.
- Adults benefit from receiving care from physicians who are trained and experienced in adult medicine.

# Barriers to transitioning:

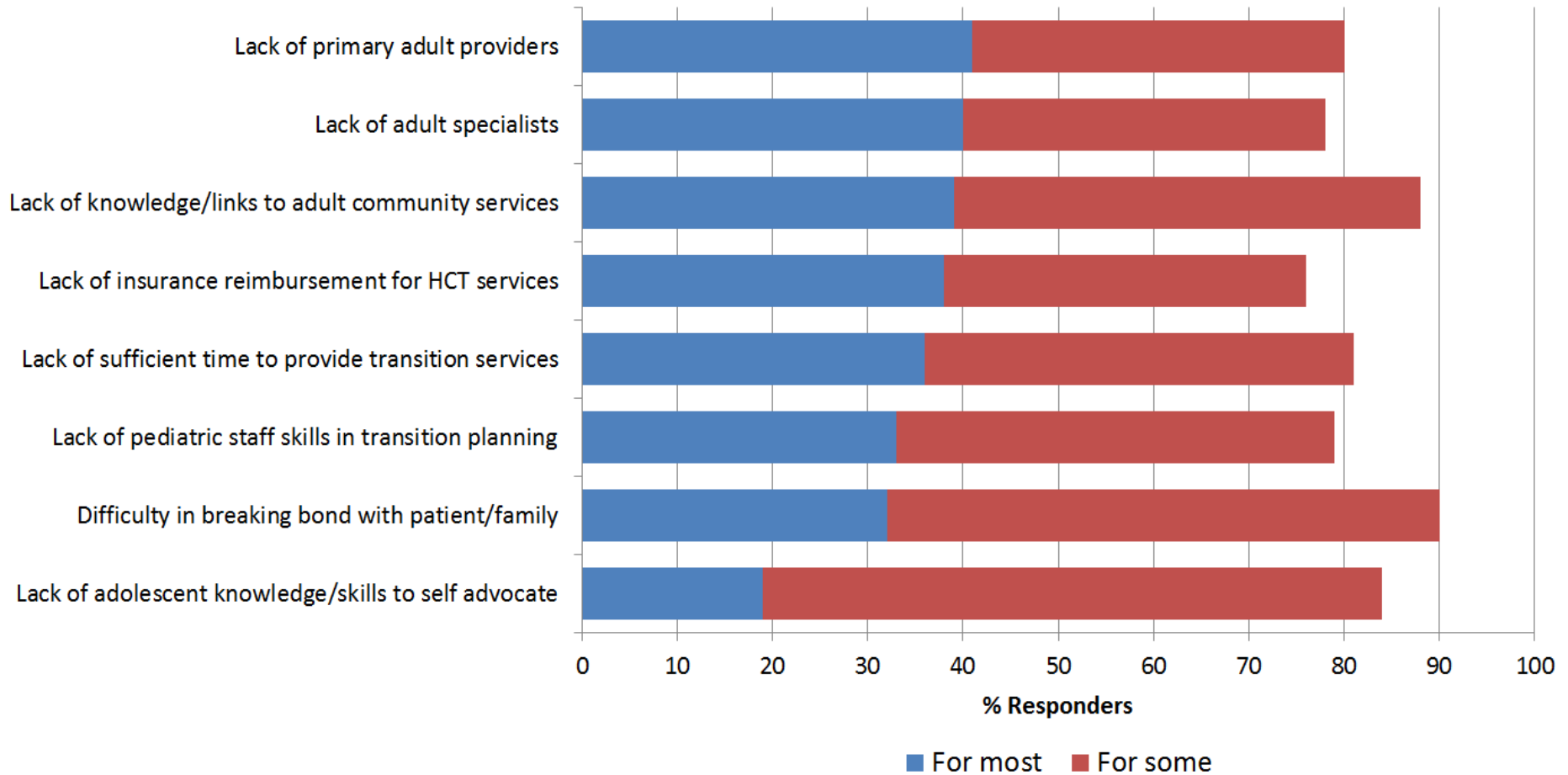
1. Pediatric provider(s)
2. Adult provider(s)
3. Patient and family



# Barrier: Pediatric providers

- Have long-standing relationships with patients and families
- May believe that their knowledge and/or skills are preferable for the care of the chronic condition regardless of the patient's age
- May be unfamiliar with community resources or lack the time/knowledge to effectively coordinate the transition process
- Patients and families may have more contact with subspecialists than PCPs

## Barriers Affecting the Provision of Transition Support Services in Pediatric Practices



- [https://www.aap.org/en-us/professional-resources/Research/Documents/PS71transition\\_care\\_factsheet.pdf](https://www.aap.org/en-us/professional-resources/Research/Documents/PS71transition_care_factsheet.pdf)

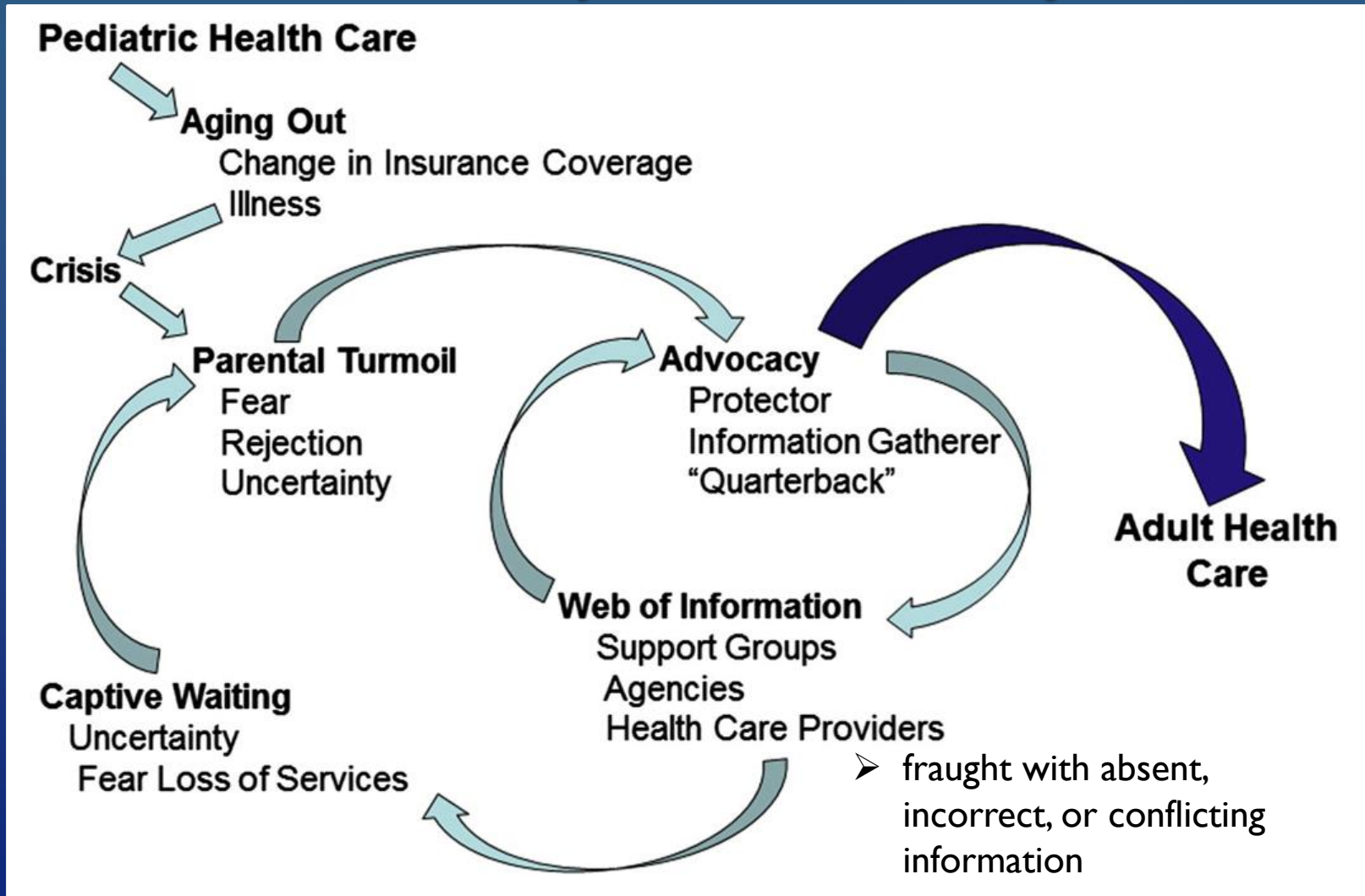
## Barrier: Adult providers

- Many pediatric-onset epilepsy syndromes have different treatments and different adult outcomes with cognitive and other co-morbidities
- Adult epilepsy care providers may have had little training in childhood epilepsy, and they may be intimidated by the complexity of pediatric epilepsies that differ considerably from the typical adult with focal epilepsy of temporal lobe origin.
- Capitated reimbursement systems serve as a disincentive
- May lack support from the adult hospital or other subspecialists

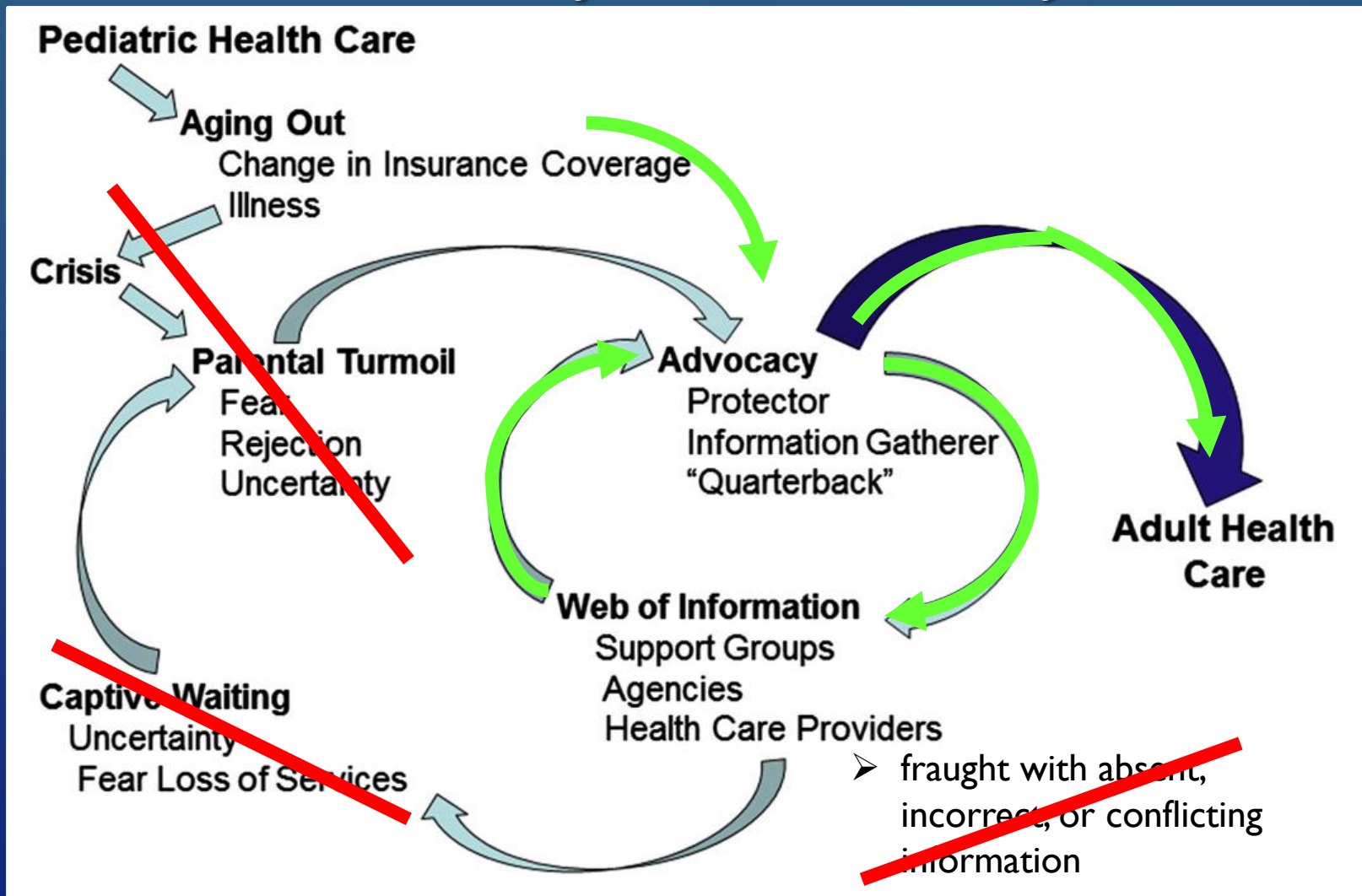
# Barrier: Patients and families

- Familiarity and comfort with pediatric health care providers.
- Different practice styles between pediatric and adult health care providers

# Barrier: Journey of Advocacy



# Barrier: Journey of Advocacy





# Barrier: Journey of Advocacy

Parents identified three broad sources of information:

- Health care providers
  - Physicians were helpful in the transition process from “a physician’s standpoint—not from a red tape standpoint.”
  - Social workers were helpful in providing information about potential community resources
- Insurance/funding agencies
- Support groups were the most helpful sources of information overall
  - “This is where you get all of your information... You get more information from parent groups than any other place.”

# Consensus Statement Goal:

To ensure that by the year 2010 all physicians who provide primary or subspecialty care to young people with special health care needs

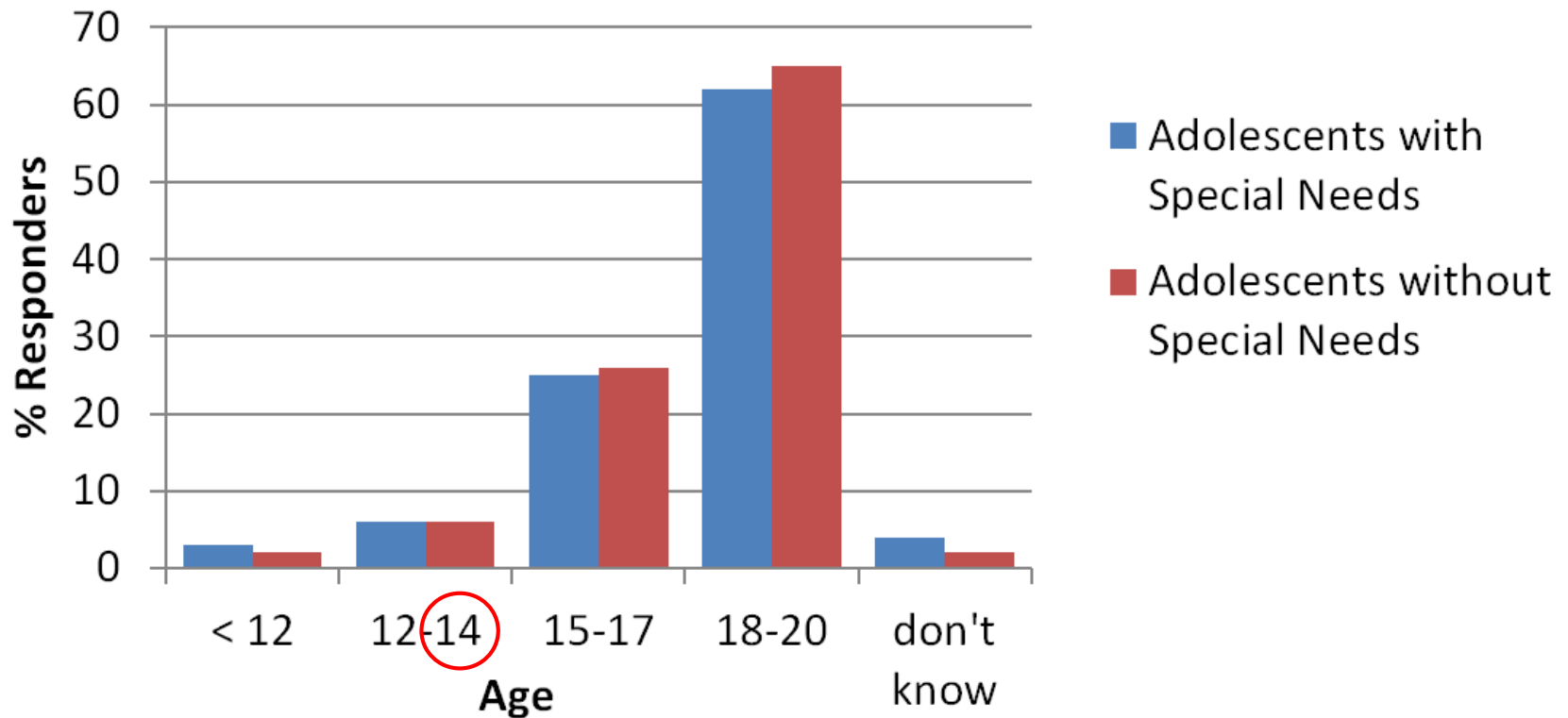
- 1) understand the rationale for transition from child-oriented to adult-oriented health care;
- 2) have the knowledge and skills to facilitate the process; and
- 3) know if, how, and when transfer of care is indicated.

# How Are We Doing?

# How Are We Doing?

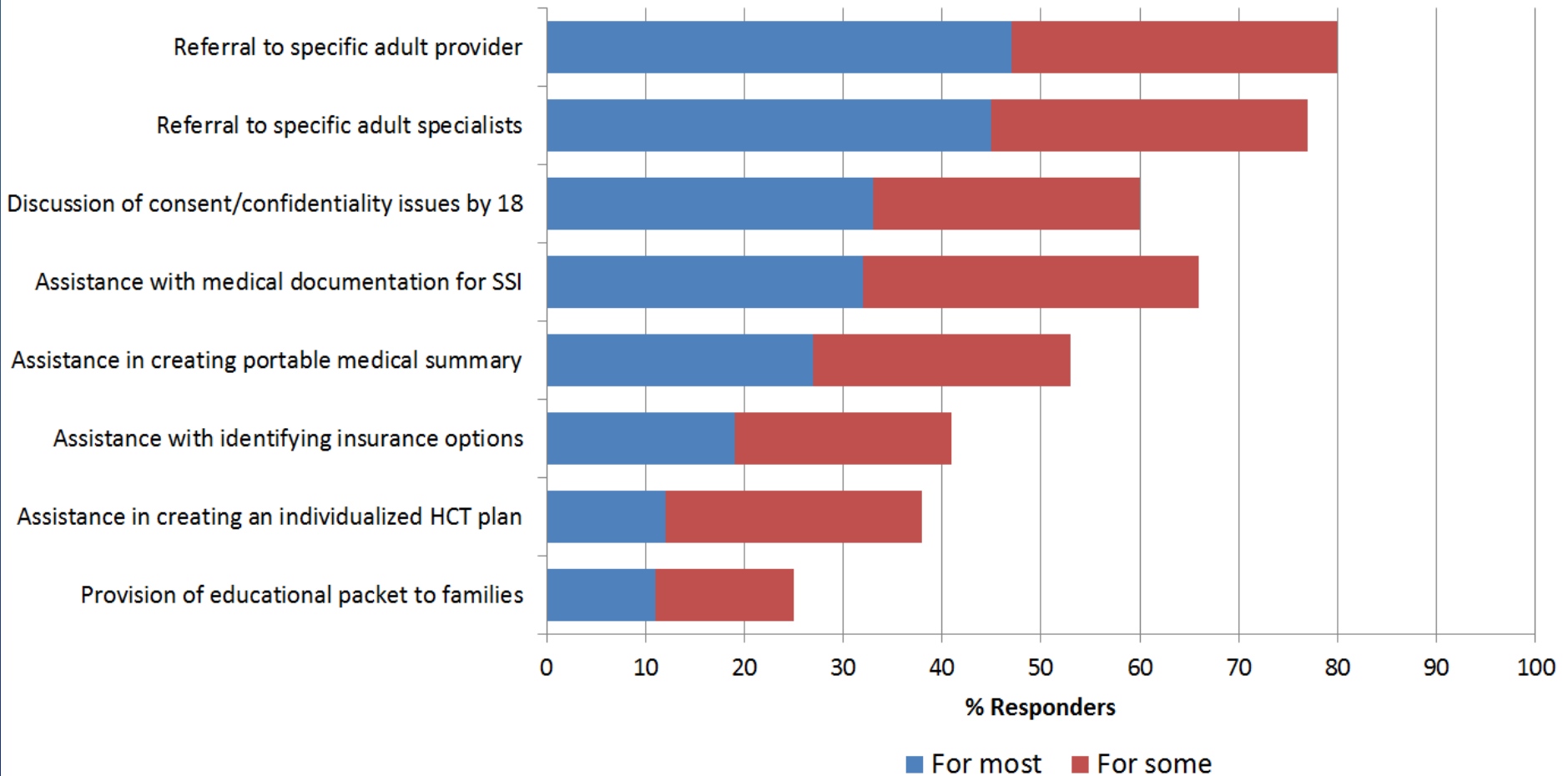


## Age at which Pediatricians Think Transition Planning Should Begin



- [https://www.aap.org/en-us/professional-resources/Research/Documents/PS71transition\\_care\\_factsheet.pdf](https://www.aap.org/en-us/professional-resources/Research/Documents/PS71transition_care_factsheet.pdf)

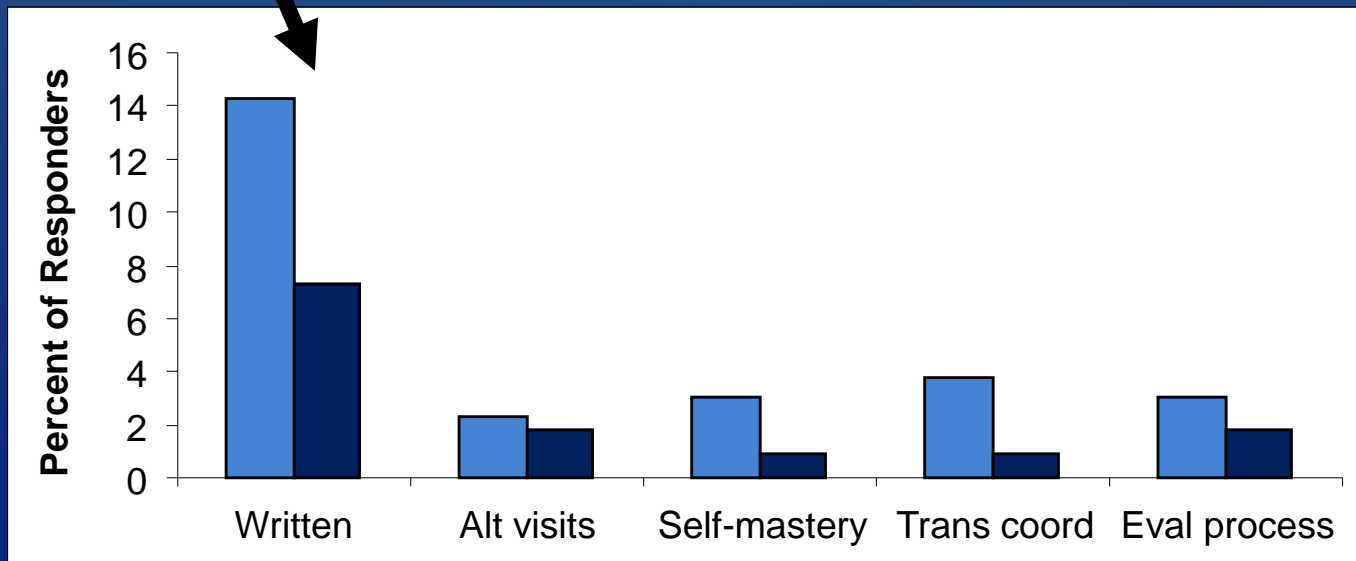
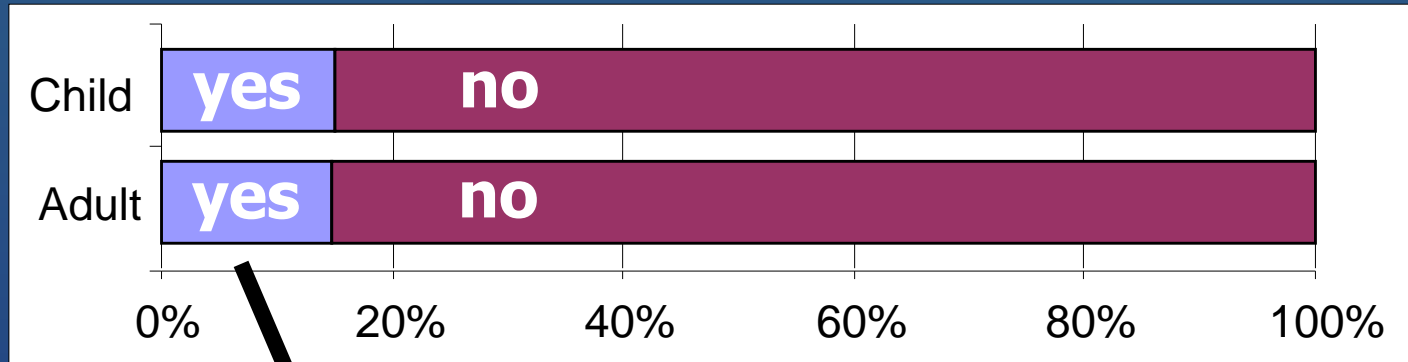
## Transition Support Services Offered in Pediatric Practices to Adolescents with Special Needs



- [https://www.aap.org/en-us/professional-resources/Research/Documents/PS71transition\\_care\\_factsheet.pdf](https://www.aap.org/en-us/professional-resources/Research/Documents/PS71transition_care_factsheet.pdf)

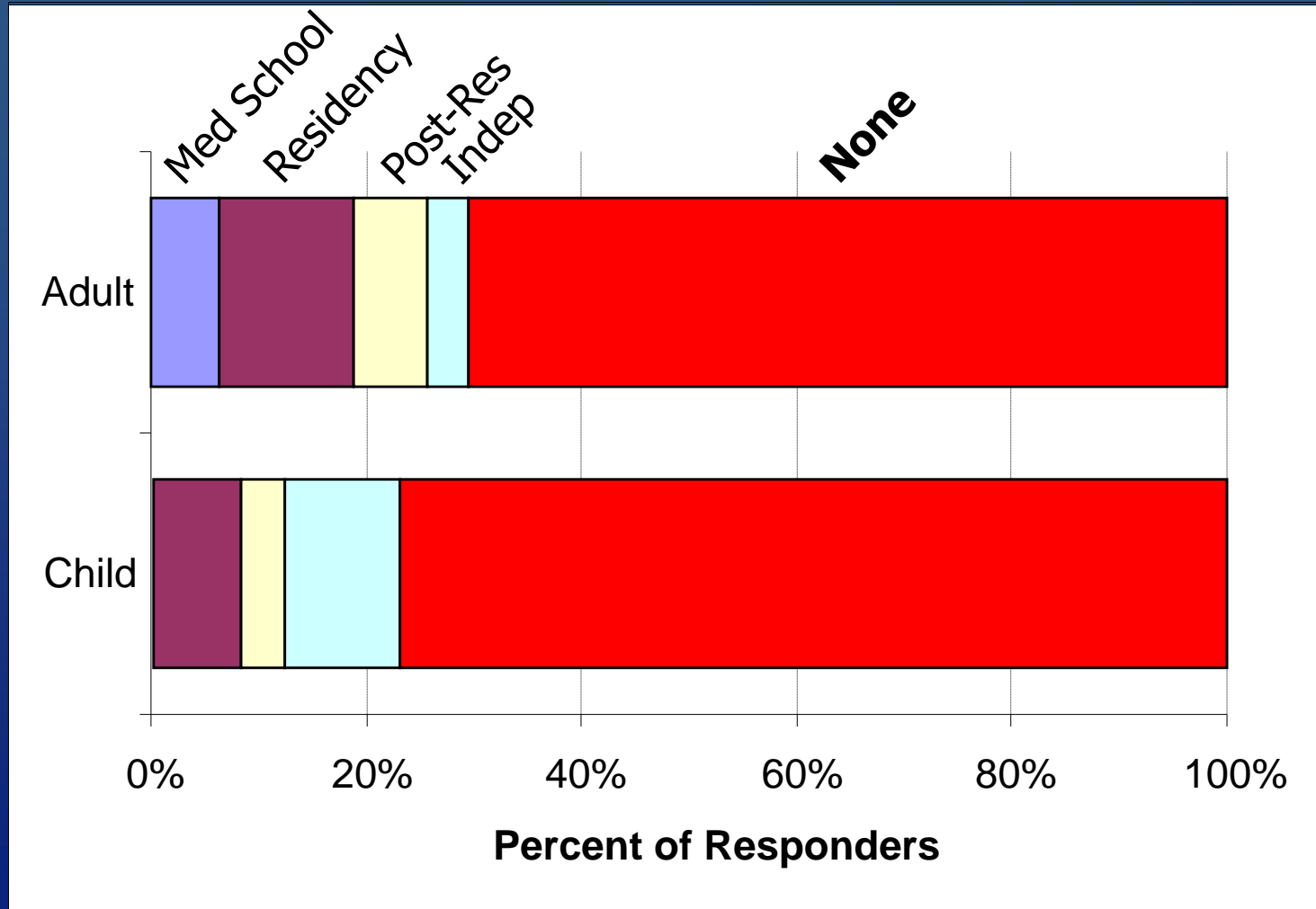
# Transition Survey 2010:

Do you have a standard transition process?



# Transition Survey 2010:

Where did you learn about patient transition?





# What Can You Do?

Family responsibilities in health care transition center on three main areas:

- **Keeping and updating a medical record**
- Preparing youth to self-provide as much of their health care as possible
- Knowing and meeting time deadlines for legal and insurance matters

keeping a medical history

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### Keeping a Medical History Provides a Roadmap to Better ...

[https://lifetimes.bcbsil.com/article/medical\\_history](https://lifetimes.bcbsil.com/article/medical_history)

Why **Keep a Medical History**? You may have a new doctor because you moved or changed health plans. You may have a new health condition that needs a specialist's care.

### My Medical — The Personal Medical Record for You, The Patient

[www.mymedicalapp.com](http://www.mymedicalapp.com)

An organized database that is yours to control. My Medical is a comprehensive record-keeping app for your personal medical information. It's the perfect replacement for unreliable paper records or various electronic systems that hold bits and pieces of your medical history.

[User Guide](#) · [iCloud Sync Guide](#) · [Image Gallery](#) · [Checkout](#)

### Keeping A Medical History and Health Diary

[www.keepingamedicaldiary.com/index.html](http://www.keepingamedicaldiary.com/index.html)

"**A Medical History** and Health Diary" was designed by an RN, to encourage patient involvement and knowledge of their health and well being.

### My Medical Manager - Create a Personal Medical History

[www.aarp.org](http://www.aarp.org) > [Health](#)

Many think of a medical record as something only a doctor's office handles. But according to Bill Thomas, M.D., a geriatric medicine and eldercare expert and AARP visiting scholar, keeping a personal health history is one of the most important steps people can take to improve the safety and quality of the health care they receive.

The best mobile medical record is ready for your desktop.



## My Medical™ for Mac

Store complete medical histories for as many people as you wish.

Keep critical and hard-to-remember information on hand all the time.

Track and chart test results and vital signs.

Send your records to the doctor with a click of a button.

[Learn more about My Medical.](#)

 [Or download it now!](#)


An organized database that is yours to control

My Medical is a comprehensive record-keeping app for your personal medical information. It's the perfect replacement for unreliable paper records or various electronic systems that hold bits and pieces of your medical history. With My Medical, any and all information that is important to you is kept together in one place.

### Existing customers

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Our List: Contact Information

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# Medical History Journal

- **Current physicians:** name, specialty, phone number, and address. Include dentist and eye doctor if you wish.
- **Current insurance information:** name, phone number, address and policy number. Include a copy of your health insurance card.
- **Current medications:** names, dosages, and instructions. Include over-the-counter supplements as they can have an interaction with prescribed medications.
- **Allergies:** name of what causes the allergy and its effects.
- **Immunizations:** List dates and immunizations/vaccines received.

# Medical History Journal

- **Physicals and major appointments:** Document the date of every complete physical, major medical appointments and the results.
- **Specific tests:** Document the date and results of medical tests such as blood work, X-rays, cultures, etc.
- **Chronic diseases and medical conditions:** Document all conditions such as asthma, high blood pressure, etc., with the date the condition was first diagnosed, symptoms, follow-up procedures, tests, changes in condition, etc.
- **Hereditary diseases:** Document any family history of major hereditary diseases that have affected children, parents, grandparents, siblings, aunts and uncles.

# Medical History Journal

- **Hospitalizations:** Keep track of dates, reason and results for any hospitalizations.
- **Surgeries:** Keep track of surgeon's name, dates, reason and results of any surgeries.
- **Accidents:** Document accidents such as a broken arm or a brain injury such as a concussion.
- It is not necessary to include minor illnesses such as colds, upset stomach, headaches, etc., unless they are chronic.

# What Can You Do?

Family responsibilities in health care transition center on three main areas:

- Keeping and updating a medical record
- Preparing youth to self-provide as much of their health care as possible
- Knowing and meeting time deadlines for legal and insurance matters



# Health Care Transition Skill Sets

## Age 12-14: New Responsibilities

### Transition Checklist

*(Check the items that are true for you.)*

- I can describe how my disability or health condition affects my daily life.
- I can name my medications (using their proper names), and the amount and times I take them.
- I answer at least one question during a health care visit.
- I have talked with my doctors or nurses about going to different doctors when I am an adult.
- I manage my regular medical tasks at school.
- I can call my primary care doctor's or specialist's office to make or change an appointment.

## Age 15-17: Practicing Independence

### Transition Checklist

*(Check the items that are true for you.)*

- I keep a personal health notebook or medical journal.
- I reorder my medications when my supply is low and call my doctor when I need a new prescription.
- I answer many of the questions during a health care visit.
- I spend most of the time alone with the doctor(s) during health care visits.
- I tell my doctors I understand and agree with the medicines and treatments they suggest.
- I know if my doctors do not take care of patients who are older than a certain age (for example, 21).
- I regularly do chores at home.
- I can tell someone the difference between a primary care doctor and a specialist.

## Age 18+: Taking Charge

### Transition Checklist

*(Check the items that are true for you.)*

- I can tell someone the effects that getting older may have on my disability or health condition.
- I can tell someone about medications that I should not take because they might interact with the medications I take.
- I am alone with the doctor(s) or choose who is with me during health care visits.
- I answer all the questions during a health care visit.
- I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
- I manage all of my regular medical tasks outside the home (school, work).
- I can tell someone what new legal rights and responsibilities I gained when I turned 18 years old (sign medical consent forms, make medical decisions by myself).
- I can tell someone how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (such as be a full-time student).

# Age 12-14: New Responsibilities

- ✓ I can describe how my disability or health condition affects my daily life.
- ✓ I can name my medications (using their proper names) and the amount and times I take them.
- ✓ I can answer at least one question during a health care visit.
- ✓ I manage my regular medical tasks at school.
- ✓ I have talked with my doctors or nurses about going to different doctors when I am an adult.
- ✓ I can call my primary care doctor's or specialist's office to make or change an appointment.

# Age 12-14: New Responsibilities

- ✓ I can describe how my disability or health condition affects my daily life.
- ✓ I can name my medications (using their proper names) and the amount and times I take them.
- ✓ I can answer at least one question at a health care visit.
- ✓ I manage my regular medical treatment.
- ✓ I have talked with my doctors or nurses about going to different doctors when I am an adult.
- ✓ I can call my primary care doctor's or specialist's office to make or change an appointment.



# Age 12-14: New Responsibilities

- ✓ I can describe how my disability or health condition affects my daily life.
- ✓ I can name my medications (their proper names) and the amount and how often to take them.
- ✓ I can understand at least one question from a health care provider at a medical visit.
- ✓ I manage my regular medical treatments.
- ✓ I have talked with my doctors or nurses about going to different doctors when I am an adult.
- ✓ I can call my primary care doctor's or specialist's office to make or change an appointment.



# Age 12-14: New Responsibilities

- ✓ I can describe how my disability or health condition affects my daily life.
- ✓ I can name my medications (using their proper names) and the amount and times I take them.
- ✓ I can answer at least one question during a health care visit.
- ✓ I manage my regular medical tasks at school.
- ✓ I have talked with my doctors or nurses about going to different doctors when I am an adult.
- ✓ I can call my primary care doctor's or specialist's office to make or change an appointment.

# Age 15-17: Practicing Independence

- ✓ I answer many of the questions at a health care visit.
- ✓ I spend most of the time alone with doctors during health care visits.
- ✓ I tell my doctors I understand and agree with the medications and treatments they suggest.
- ✓ I regularly do chores at home.
- ✓ I can tell someone the difference between a primary care doctor and a specialist.
- ✓ I know if my doctors do not take care of patients who are older than a certain age (for example, 21).

# Age 15-17: Practicing Independence

- ✓ I reorder my medications when my supply is low and call my doctor when I need a new prescription.
- ✓ I keep a personal health notebook or journal.

# Age 18+: Taking Charge

- ✓ I can tell someone the effects that getting older may have on my disability or health condition.
- ✓ I can tell someone about medications that I should not take because they might interact with the medications that I take.
- ✓ I am alone with the doctors or choose who is with me during health care visits.
- ✓ I answer all the questions during a health care visit.
- ✓ I manage all of my regular medical tasks outside the home (school, work).



# Age 18+: Taking Charge

- ✓ I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
  - Discuss with your providers when you should consider transferring care to an adult provider.
  - Ask your primary care provider who on his/her staff can assist you in care coordination.
  - Talk to other families and young adults with similar needs and disabilities to help identify an appropriate adult health care provider.
  - Schedule interview visits with health care providers before transferring care.

# Health Care Transition Skill Sets

## Age 12-14: New Responsibilities

### Transition Checklist

*(Check the items that are true for you.)*

- I can describe how my disability or health condition affects my daily life.
- I can name my medications (using their proper names), and the amount and times I take them.
- I answer at least one question during a health care visit.
- I have talked with my doctors or nurses about going to different doctors when I am an adult.
- I manage my regular medical tasks at school.
- I can call my primary care doctor's or specialist's office to make or change an appointment.

## Age 15-17: Practicing Independence

### Transition Checklist

*(Check the items that are true for you.)*

- I keep a personal health notebook or medical journal.
- I reorder my medications when my supply is low and call my doctor when I need a new prescription.
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## Age 18+: Taking Charge

### Transition Checklist

*(Check the items that are true for you.)*

- I can tell someone the effects that getting older may have on my disability or health condition.
- I can tell someone about medications that I should not take because they might interact with the medications I take.
- I am alone with the doctor(s) or choose who is with me during health care visits.
- I answer all the questions during a health care visit.
- I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
- I manage all of my regular medical tasks outside the home (school, work).
- I can tell someone what new legal rights and responsibilities I gained when I turned 18 years old (sign medical consent forms, make medical decisions by myself).
- I can tell someone how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (such as be a full-time student).

# Health Care Transition Skill Sets

Age 12-14: New Responsibilities

## Transition Checklist

(Check the items that are true for you.)

- I can describe how my disability or health condition affects my daily life.
- I can name my medications (using their proper names), and the amount and times I take them.
- I answer at least one question during a health care visit.
- I have talked with my doctor(s) about going to different health care facilities when I am an adult.
- I understand and agree with the health care plan and treatments I am given.
- I know if my doctors do not take care of patients who are older than a certain age (for example, 21).
- I regularly do chores at home.
- I can tell someone the difference between a primary care doctor and a specialist.

Age 15-17: Practicing Independence

## Transition Checklist

(Check the items that are true for you.)

- I keep a personal health notebook or medical journal.
- I reorder my medications when my supply is low and call my doctor when I need a new prescription.
- I answer many questions during a health care visit.
- I have talked with my doctor(s) about going to different health care facilities when I am an adult.
- I understand and agree with the health care plan and treatments I am given.
- I know if my doctors do not take care of patients who are older than a certain age (for example, 21).
- I regularly do chores at home.
- I can tell someone the difference between a primary care doctor and a specialist.

Age 18+: Taking Charge

## Transition Checklist

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- I can tell someone how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (such as be a full-time student).
- I can tell someone what new legal rights and responsibilities I gained when I turned 18 years old (sign medical consent forms, make medical decisions by myself).
- I manage all of my regular medical tasks outside the home (school, work).
- I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
- I answer all the questions during a health care visit.
- I reorder my medications when my supply is low and call my doctor when I need a new prescription.
- I keep a personal health notebook or medical journal.
- I can tell someone the difference between a primary care doctor and a specialist.
- I answer many questions during a health care visit.
- I understand and agree with the health care plan and treatments I am given.
- I know if my doctors do not take care of patients who are older than a certain age (for example, 21).
- I regularly do chores at home.
- I can tell someone the difference between a primary care doctor and a specialist.

**How well do I manage my own health care?  
(Please check off box)**

I can do this

I will learn to do this

I can do this with supportive technology

Someone will need to do this for me

# What Can You Do?

Family responsibilities in health care transition center on three main areas:

- Keeping and updating a medical record
- Preparing youth to self-provide as much of their health care as possible
- Identifying what assistance may be needed
- Knowing and meeting time deadlines for legal and insurance matters

# Age 18+: Taking Charge

- ✓ I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
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# What Can You Do?

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- **Knowing and meeting time deadlines for legal and insurance matters**

# Transition: Legal Issues



After a child turns 18 years old, parents no longer have automatic access to their child's personal health information. After 18, health care providers are required by law to respect the right to confidentiality of personal health information. Health care providers cannot provide this information to parents unless they have written permission to do so.

The right to privacy of personal health information can help to prompt you and your child to discuss the changes in responsibility that will occur on their 18th birthday. This discussion can make clear the limitations that parents face and how a young adult at age 18 becomes the responsible person for medical decision-making.

# Transition: Legal Issues

For some young adults who have difficulty making informed decisions, informal supports may be sufficient. These can involve a network of family and friends providing informal support and guidance. It is important to recognize these informal networks must still operate within privacy laws.

Steps for developing and maintaining such an informal network include signing “release of information” forms so that family members will have access to medical information if the young adult so chooses.



# Transition: Legal Issues

- Release of medical records and information.
  - Ordinary health care power of attorney (HCPOA).
    - Health care power of attorney with special provisions restricting the right to revoke and the right to refuse.
      - Health care power of attorney with special provisions making it effective even when person is not incapacitated.
        - Court-appointed conservator.
          - Conservator of the estate
          - Conservator of the person
        - Court-appointed guardian.
          - Court ordered commitment/protective placement.

# Transition: Legal Issues

Other young adults whose ability to make informed decisions is more limited, may need the formal supports that are provided through guardianship. Guardianship is a lengthy legal process that involves submitting a formal application to the county probate court. **This petition should be filed 6 months before an adolescent turns 18 to maintain guardianship or to initiate conservatorship.**

# Age 18+: Taking Charge

- ✓ I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
- ✓ I can tell someone what new legal rights and responsibilities I gained when I turned 18 years old (sign medical consent forms, make medical decisions by myself).
- ✓ I can tell someone how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (such as be a full-time student).

# Private Insurance:

- Under the ACA provision, otherwise independent young adults can receive health care coverage through their parent's plan up until the age of 26.
- Many insurance plans may either not cover certain essential health services (e.g. speech, language and occupational therapies) or place a cap on and limit important benefits like mental and behavioral health care, rehabilitative therapies, and prescription drugs.
- If personal care workers, nurses and/or therapists help you at home, you will want to ask about whether these services will change or end when you become an adult.

# Private Insurance:

## ADULT DISABLED DEPENDENT CHILD

- Youth over 18 may continue on family plan if dependent for life and unable to achieve substantial gainful employment.
- Check plan before child turns 18.
- Must be on the family plan prior to turning 18.
- Annual re-certification - disability & dependent

40 states have this provision mandated in state health insurance statute:

AZ, AR, CA, **CT**, FT, GA, HI, ID, IL, IN, LA, ME, MD, MA, MI, MN, MS, MO, MT, NE, NV, NH, NJ, NM, NY, NC, ND, OH, OR, RI, SC, SD, TN, TX, UT, VT, VA, VT, WA, WI and WY

# Medical Assistance:

## **NAVIGATING MEDICARE AND MEDICAID, 2005**

A Resource Guide  
for People with  
Disabilities,  
Their Families,  
and Their Advocates



February 2005

# Medical Assistance:

**“Medicare and Medicaid are extremely complicated and confusing programs.”**

## NAVIGATING MEDICARE AND MEDICAID, 2005

A Resource Guide  
for People with  
Disabilities,  
Their Families,  
and Their Advocates



February 2005

# Medical Assistance:

Young adults who receive **SSI** do not automatically qualify for **SSI** as an adult. An adult eligibility determination needs to be made for individuals who are 18 or older. This means that young adults who receive **SSI** need to reapply for the benefit during transition.

To prevent interruption of benefits, contact the Social Security office about 3 months before your 18th birthday.

## NAVIGATING MEDICARE AND MEDICAID, 2005

A Resource Guide  
for People with  
Disabilities,  
Their Families,  
and Their Advocates



February 2005



# Medical Assistance:

**Medicare** eligibility rules for persons under age 65 with disabilities require individuals to have received Social Security disability benefits for 5 months before becoming Medicare eligible.

Once they have received Social Security disability for 5 months, they must wait another 24 months for Medicare coverage to begin.

## NAVIGATING MEDICARE AND MEDICAID, 2005

A Resource Guide  
for People with  
Disabilities,  
Their Families,  
and Their Advocates



February 2005

# Medical Assistance:

Every state plays a significant role in financing **Medicaid** services.

Each one has broad discretion in designing and administering its Medicaid program. Within broad national guidelines set by the federal government each state:

1. Establishes its own eligibility standards.
2. Determines the type, amount, duration, and scope of services it will provide.
3. Sets the rate of payment for services.
4. Administers its own program.

## NAVIGATING MEDICARE AND MEDICAID, 2005

A Resource Guide  
for People with  
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and Their Advocates



February 2005

Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

## News & Announcements

Are you ready to transition to adult health care?



[Take Our Quiz!](#)

### NEW Preventive Care and Transition Toolkit Available

Got Transition has released a new Preventive Care and Transition Toolkit that provides suggested questions and anticipatory guidance for clinicians to introduce health care transition during preventive visits with adolescents and young adults. [more>](#)

### UPDATED: 2018 Transition Coding and Reimbursement Tip Sheet Available

Got Transition and the American Academy of Pediatrics released its updated 2018 Transition Coding and Reimbursement Tip Sheet, with current CPT codes, fee data and RVUs, and new clinical vignettes. [more>](#)

### Annual Transition Conferences: Save the Date and Call for Abstracts

Two annual conferences on health care transition will be held in late October in Houston, TX. [more>](#)

### Got Transition Webinar Series

Registration is open for Got Transition's new webinar series, "Health Care Transition & Title V Care Coordination Initiatives." [more>](#)

## Health Care Providers

Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.



Customize the Six Core Elements of Health Care Transition to meet your patients' and practice's needs!

Incorporating Health Care Transition Services into Preventive Care for Adolescents and Young Adults: A Toolkit for Clinicians

## Youth & Families

Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.



Turning 18: What it Means for Your Health

The "Medical ID" Feature on Apple's Health app

The "Medical ID" app for Android phones

## Researchers & Policymakers

Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.



NEW Got Transition Webinar Series

2017 Report on Innovative State Title V Transition Efforts

State Title V Transition Information and Resources

www.childneurologyfoundation.org/TRANSITIONS/

http://www.childneurologyfoundation.org/TRANSITIONS/

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Child Neurology FOUNDATION  
Creating a Community of Support

PATIENTS OR CAREGIVERS ADVOCACY GROUPS HEALTH CARE PROVIDERS

## Transition of Care

Each patient transitioning from a child neurologist to an adult neurologist will have unique experiences and needs. CNF's Transition of Care Program—its largest and most diverse program—*helps to support youth, families, and child neurology teams in the medical transition from pediatric to adult health care systems.*

**NEW! CNF was featured in the April Autism Awareness Issue of *Exceptional Parent Magazine*: “The Neurologist’s Role in Supporting Transition of Adult Health Care”**

**Are you a parent or caregiver of a person 12-30 years of age living with a complex neurologic condition?**

# STAY A STEP AHEAD

## Prepare for the Future of Your Epilepsy Care

When you have epilepsy or care for someone with epilepsy, it's important to plan for the future. To be prepared, you or your child should be ready to **transition** from a child epilepsy doctor to one for an adult. It may seem like a long time from now, but creating a transition plan needs to start early. That way, everyone can be ready when care changes hands. Being involved helps you stay on track and feel in control of the future, too. It's a win-win!

Eisai has partnered with the **Child Neurology Foundation** to help you learn more about the transition process from the steps below.

### START TALKING TRANSITION

STEP  
**1**



Transition takes place over  
**SEVERAL  
YEARS**



Conversations with your epilepsy  
care team should start no later than

**AGE 12**

so that everyone can get  
on the same page early



Make sure to

**KEEP TRACK**

of all conversations including seizure  
and treatment history



**I CARE FOR SOMEONE WITH EPILEPSY**

[Click for More >](#)



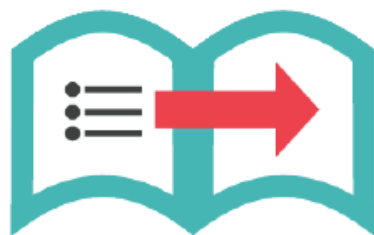
**I AM SOMEONE WITH EPILEPSY**

[Click for More >](#)

## PREPARE EVERY YEAR FOR SELF-MANAGEMENT

STEP

2



Do a yearly review of **self-management skills** with your team – It's important to

### TRACK THESE SKILLS EVERY YEAR

to get ready for future responsibilities



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## STAY EDUCATED

STEP

3



Begin creating a **transition plan** at age 13 and

### REVIEW IT EACH YEAR



Focus on learning as much as you can to

### GET READY FOR CHANGING CARE

to an adult doctor



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## BIG DECISIONS

STEP

4



Make sure that self-care is a possibility &  
**DISCUSS LEGAL  
RESPONSIBILITY  
BY AGE 14**



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## WORK TOGETHER

STEP

5

Work together with your entire team to put together a solid transition plan. It should include topics like:



Overall health



Financial help



Legal help



Education



Employment



Housing



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## BE IN THE KNOW

STEP

6



### DEVELOP & CONFIRM

the **neurologic** portions of  
your transition plan



### UPDATE YOUR TRANSITION PLAN YEARLY



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[Click for More >](#)



I AM SOMEONE WITH EPILEPSY

[Click for More >](#)

## PICK A NEW TEAM

STEP

7



Approximately

### 1-2 YEARS BEFORE IT'S TIME FOR YOU TO TRANSFER TO AN ADULT DOCTOR,

work with your epilepsy care team to pick a new adult team



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## CONFIRM AND COMMUNICATE

STEP

8



## CONFIRM THE TRANSFER OF CARE

and start going to the new adult epilepsy doctor



**I CARE FOR SOMEONE WITH EPILEPSY**  
Click for More >



**I AM SOMEONE WITH EPILEPSY**  
Click for More >

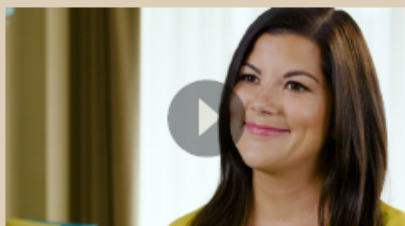


By staying a step ahead and following this guide for transition, Eisai and the Child Neurology Foundation hope that patients, doctors and caregivers will go through a successful transition.



### Watch:

for tips about having  
a **successful transition**,  
[check out this link:](#)



### Learn more:

about the transition process at  
[childneurologyfoundation.org](http://childneurologyfoundation.org)  
[advancingepilepsycare.com](http://advancingepilepsycare.com)



## Connecticut Medical Home Initiative for Children & Youth with Special Health Care Needs

### Who is eligible?

Children & youth age 0 to 21 who have, or are at increased risk for, a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

### Services available?

**All families** of eligible children and youth with special health care needs (CYSHCN), regardless of income, will receive a respectful working partnership with you and your child's medical home; care coordination services and family support referrals.

**Uninsured or underinsured families, who fall within income guidelines**, can also benefit from payment for limited services (i.e. durable medical equipment, prescriptions, and special nutritional formulas). Contact the **Connecticut Medical Home Initiative at FAVOR, Inc. at 1-855-436-6544 (toll free)**.

#### SOUTHWEST

Stamford Hospital  
Stamford

1-866-239-3907  
(toll free)

#### SOUTH CENTRAL

Family Centered  
Services of CT, Inc.  
New Haven

1-877-624-2601  
(toll free)

#### EASTERN

United Community and  
Family Services, Inc.  
Norwich

1-866-923-8237  
(toll free)

#### NORTH CENTRAL

Connecticut Children's  
Medical Center  
Hartford

1-877-835-5768  
(toll free)

#### NORTHWEST

St. Mary's Hospital  
Waterbury

1-866-517-4388  
(toll free)

### United Way of Connecticut's Child Development Infoline

*The central access point for Connecticut's Medical Home Initiative for CYSHCN.  
Provides information about medical, educational and recreational resources*

**1-800-505-7000**

### Connecticut Family Support Network

*Contact for family support, information and advocacy at 877- FSN-2DAY*

**Connecticut Medical Home Initiative for Children and Youth with Special Health Care Needs  
Regional Town Listings**

<b>SOUTHWEST REGION</b>	<b>SOUTH CENTRAL REGION</b>	<b>EASTERN REGION</b>	<b>NORTH CENTRAL REGION</b>	<b>NORTHWEST REGION</b>
<b>Stamford Health Systems</b>	<b>Family Centered Services of CT</b>	<b>United Community and Family Services</b>	<b>Connecticut Children's Medical Center</b>	<b>St. Mary's Hospital</b>
<b>Stamford</b>	<b>New Haven</b>	<b>Norwich</b>	<b>Hartford</b>	<b>Waterbury</b>
<b>Toll Free 866-239-3907</b>	<b>Toll Free 877-624-2601</b>	<b>Toll Free 866-923-8237</b>	<b>Toll Free 877-835-5768</b>	<b>Toll Free 866-517-4388</b>
BRIDGEPORT	ANSONIA	ASHFORD	ANDOVER	BARKHAMSTED
DARIEN	BETHANY	BOZRAH	AVON	BEACON FALLS
EASTON	BRANFORD	BROOKLYN	BERLIN	BETHEL
FAIRFIELD	CHESTER	CANTERBURY	BLOOMFIELD	BETHLEHEM
GREENWICH	CLINTON	CHAPLIN	BOLTON	BRIDGEWATER
MONROE	CROMWELL	COLCHESTER	BRISTOL	BROOKFIELD
NEW CANAAN	DEEP RIVER	COLUMBIA	BURLINGTON	CANAAN
NORWALK	DERBY	COVENTRY	CANTON	CHESHIRE
STAMFORD	DURHAM	DANIELSON	EAST GRANBY	COLEBROOK
STRATFORD	EAST HADDAM	EAST LYME	EAST HARTFORD	CORNWALL
TRUMBULL	EAST HAMPTON	EASTFORD	EAST WINDSOR	DANBURY
WESTON	EAST HAVEN	FRANKLIN	ELLINGTON	GOSHEN
WESTPORT	ESSEX	GRISWOLD	ENFIELD	HARTLAND
WILTON	GUILFORD	GROTON	FARMINGTON	HARWINTON
	HADDAM	HAMPTON	GEORGETOWN	KENT
	HAMDEN	KILLINGLY	GLASTONBURY	LITCHFIELD
	KILLINGWORTH	LEBANON	GRANBY	MIDDLEBURY
	LYME	LEDYARD	HARTFORD	MORRIS
	MADISON	LISBON	HEBRON	NAUGATUCK
	MERIDEN	MANSFIELD	MANCHESTER	NEW FAIRFIELD
	MIDDLEFIELD	MONTVILLE	MARLBOROUGH	NEW HARTFORD
	MIDDLETOWN	MOOSUP	NEW BRITAIN	NEW MILFORD
	MILFORD	NEW LONDON	NEWINGTON	NEWTOWN
	NEW HAVEN	NIANTIC	PLAINVILLE	NORFOLK
	NORTH BRANFORD	NORTH STONINGTON	PLYMOUTH	NORTH CANAAN
	NORTH HAVEN	NORWICH	ROCKY HILL	OXFORD
	OLD LYME	PLAINFIELD	SIMSBURY	PROSPECT
	OLD SAYBROOK	POMFRET	SOMERS	REDDING
	ORANGE	PRESTON	SOUTH WINDSOR	RIDGEFIELD
	PORTLAND	PUTNAM	SOUTHINGTON	ROXBURY
	SEYMOUR	SALEM	STAFFORD	SALISBURY
	SHELTON	SCOTLAND	SUFFIELD	SHARON
	WALLINGFORD	SPRAGUE	TOLLAND	SHERMAN
	WEST HAVEN	STERLING	VERNON	SOUTHBURY
	WESTBROOK	STONINGTON	WEST HARTFORD	THOMASTON
	WOODBIDGE	THOMPSON	WETHERSFIELD	TORRINGTON
		UNCASVILLE	WINDSOR	WARREN
		UNION	WINDSOR LOCKS	WASHINGTON
		VOLUNTOWN		WATERBURY
		WATERFORD		WATERTOWN
		WILLINGTON		WINCHESTER
		WILLIMANTIC		WOLCOTT
		WINDHAM		WOODBURY
		WOODSTOCK		

[http://www.ct.gov/dph/lib/dph/family\\_health/children\\_and\\_youth/pdf/cmhi\\_regional\\_town\\_listings\\_color\\_2013.pdf](http://www.ct.gov/dph/lib/dph/family_health/children_and_youth/pdf/cmhi_regional_town_listings_color_2013.pdf)

# Challenges 2018:

- How do we get health care providers to initiate transition services sooner for youth with special health care needs and to conduct them in a more organized and comprehensive fashion?
- How can we educate and empower patients and families to direct health care transition?
- How do we provide more coordinated services for adults with special health care needs?

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