Transition from Adolescent to Adult Health Care

Allyson Bolduc, MD
Past President of the Vermont Academy of Family Physicians

Jill Rinehart, MD FAAP
President of the Vermont American Academy of Pediatrics

Vermont Family Network Webinar
August 31, 2016
Today’s objectives

• What are transitions
• Why does a smooth transition matter
• National priority
• Local projects
• Five steps to a good transition
• Conclusion
What are transitions?

- The process of changing from one state or condition to another
  - School – middle school to high school to postgraduate
  - Work – school to work, continuing education while working
  - Relationships – child with adult parents/guardian, peers, bosses and teachers
  - Independent living – home to apartment, group living
  - Insurance – coverage changes at age 18 or 25
Key Factors in Transition

• Need for planning
• Taking small steps over time
• Increasing responsibility of the patient when possible
• Increasing independence
Why does it matter?

- Maximize education/future planning
- Work plan
- Maximize health without interruption
- No gaps in health insurance
- No gaps in ongoing healthcare (new provider)
Identifying a Population Health Problem

1. Ages 18-26 are high health risk population

2. Vermont school nurses survey tells us:
   A. Well child visits from grades K through 12 decrease from 78% to 48%
   B. 24,000 adolescents in grades 9-12 in Vermont
   C. Bright Futures recommends annual well visits through age 21

3. Times of major transitions (school to work or school, leaving home, new environments, etc.) are often problematic
Challenges to VT Transition “system”

- Bright Futures Guidelines for Pediatric and Adolescent Care is for birth-21
- Currently age 14 and over is “adult” for UVMMC Pediatric Surgery
- Currently age 18 and over is “adult” for UVMMC Intensive Care Unit
- Currently age 18 and over is “adult” for UVMMC psychiatry unit
- Currently age 18 and over is many other UVMMC adult subspecialties
- Affordable Care Act allows youth to remain on parent’s policies through age 25
- IEP’s are effective for intellectual disabilities through age 21
- Pregnancy, parenthood, emancipation, guardianship
National Priorities

• Title V agencies represent every region of the country

• Of the 2015 Block grants
  • 32 states selected health care transition as a priority
  • 24 of 32 focus on youth with special needs
  • 8 focus on youth in transition in general
• Clinical report 2002 - a consensus statement on health care transitions


• Dr. Matt Holder- developmental medicine model
National Priorities, con’t.

• Tennessee – Family Medicine with I/DD Adults (tools for Family Medicine; tip sheet)

• Family Medicine in Worcester, MA – Bob Bell developing network of local champions for I/DD

• Center for I/DD in the Family Medicine Department?

• Nathan Bradford (MedPeds) SC, transition to FM clinic

• Laura Tickler – FM Denver AAFP transition issues with training in residency, etc (Transition training)

• Texas Children’s Hospital – transition planning tool

• ACP initiative – Patience White coordinating national effort with subspecialty groups
Bridging the Gap
There is Policy Support for Transition

• 2011 AAP/AAFP/ACP Clinical Report on Transition: “Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home”

• 2002 AAP/AAFP/ACP Policy Statement: “A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs”

• October, 2014 *Pediatrics*, “Transition Care for Children With Special Health Care Needs,” Alaina Davis, et.al

• IOM Report: Investing in the Health and Well-being of Young Adults
“Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and wellbeing for all youth, including those who have special health care needs and those who do not.”
Local Vermont Priorities

- Annual adolescent well visits is an VT Accountable Care Organization measure
- Vermont Medical Society Resolution
- American Academy of Pediatrics- VT chapter priority
- Inclusive Healthcare Partnership Project IHPP 2015 – grant and white paper
- Got Transitions Center for Healthcare Transition
- Subspecialty groups at UVMMC discussing transitions – in the planning stage
- Interdisciplinary group working on adults with special needs at UVMMC and coordination care for medically complex youth
- IRB – local pilot on transitions
Side Note

• Vermont Family Network – toolkit – planning tips for transition-age youth and their families
• Yearly guide of what to consider – IEP, Personalized learning plan, timelines
• Planning may begin in middle school
• Vermontfamilynetwork.org
• Letter from State of Vermont, Dept of Health, Children with Special Health Needs (CSHN) – reaching out at age 17 about transitions
Recommended Health Care Transition Timeline

12 Make youth and family aware of transition policy
14 Initiate health care transition planning
16 Prepare youth and parents for adult model of care and discuss transfer
18 Transition to adult model of care
18-22 Transfer care to adult medical home and/or specialists with transfer package
23-26 Integrate young adults into adult care
What about the Health Care Transition: When to begin the conversation

- Age 12 – youth and family aware of transition policy
- Age 14 – initiate health care transition planning
- Age 16 – prepare youth and parents for adult model of health care
- Age 18 – transition to Adult model of care
- Age 18-22 – transfer care to adult medical home and/or specialists with transfer package
- Age 23-26 – integrate young adults into adult care
Adult Model Care vs. Pediatric/Adolescent

- Does not mean losing its family centeredness
- Must continue to be proactive, timely, accurate problem-solving communication
- Relationship is between the young adult and the practice
- Challenge for families: the system of care seems to change
- Patient Centered Medical Home—supports care coordination and the model transitioning patients are “used to”

Into the Void
Voice of Adult self-advocates differs from their Parents

- “New Voices in Medical Advocacy Often are Patients” Wall Street Journal, July 25, 2016

- “Parent advocates of children with chronic conditions have long worked toward finding cures; adult self-advocates are shifting the focus to goals of independent work and living.”

http://www.wsj.com/articles/new-voices-in-medical-advocacy-often-are-patients-1469468317

Alison and Jodie Singer
Five steps to a good transition in health care

• Discovery
• Tracking
• Preparing
• Planning
• Transferring
Step one
Discovery
### Discovery

- Health care professional’s approach to transition
- Why change medical homes?
- Do I need to change medical homes?
- If Pediatric practice – I do need to change
- If Adult practice—relationship changes
- Pediatric practice policy on transition age
  - Every practice office should have a policy on transition
  - Some have posters, others letters
Is Your Adolescent getting READY for Life?
The Adolescent Health Supervision Visit

As your child becomes an adolescent, the hormonal shifts common during puberty result in emotional and physical changes. This transition can feel overwhelming; your teen’s health care provider is one person who can guide you both through this journey. Yearly check-ups, also called health supervision or well care visits, are often overlooked but can provide you with the tools to successfully transition your teen through adolescence.

Is a Well Care Visit a Sports Physical?
Some schools require athletes to provide proof of a physical exam before participating in sports. This exam is simply intended to evaluate one’s physical ability to safely participate in sports. Well care visits allow for a more thorough physical exam and health screen. They also provide the opportunity to address other important teen issues.

What happens during an adolescent’s Well Care Visit?
The provider will review several areas of development and preventative health topics. The provider can measure BMI and give advice about nutrition and physical activity. Well care visits through middle and high school also provide a chance to review your teen’s vaccine history and discuss other recommended vaccines. Screening tests may be recommended (vision and hearing screening, testing for anemia, or screening for hidden infections such as tuberculosis or chlamydia).
What about my adolescent’s behavior and emotional health?
Teens are surrounded by confusing messages from the media and peers who may be making unhealthy choices. This visit allows your teen the chance to discuss sensitive topics and address problems early. Some of these topics may include drugs and alcohol, eating disorders, depression, anxiety, puberty, and sexuality. The majority of teen fatal and non-fatal accidents are preventable, and well care visits can provide guidance teens need to make good decisions and decrease their risks of injury.

What can I do to protect my adolescent from risky behavior?
Reinforcing strengths or assets can protect teens from risks and help them get READY for life. Your doctor may ask your teen about their strengths:

R for Relationships: Is your teen learning to form healthy relationships with peers, teachers, and coaches? Does he feel he belongs or fits in at school and in the community? Does he have at least one adult he can go to if he is has a problem to discuss? What about romantic relationships?

E for Energy to get things done. Does your teen have enough energy to get school work done and have fun? If not, why not? Is there a health problem, not enough sleep, or could she be depressed?

A for Awareness of the world and how one fits in. Does your teen have opportunities to contribute in the family, at school, in the community? Is he developing a sense of honesty, kindness, empathy, and generosity?

D for Decision maker. Is your teen learning how to make healthy, independent decisions about her health and behavior choices? Can you help her be a better decision maker?

Y for saying Yes to healthy behaviors – Does your teen eat well, sleep well, work hard and play hard?
What can you do to help transition?

- Ready to be more independent
- Ready to be primary patient
- Spend part of each visit alone with PCP
- Find out about rights to privacy and confidentiality
- Does the practice have a written policy
Assume Ready for Independence
Step two

Tracking
Tracking

- Keep track of health information
- Calendar for appointments
- Printed medical summary (allergies, problem list, medications, etc)
- Shared Plan of Care
  - Medical Summary
  - Emergency care plan(s)
  - Eco-Map
  - Family strengths
  - Goals/Next Steps

Template

Report

Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs
An Implementation Guide

Jeanne W. McAllister, BSN, MS, MHA
What to bring to appointments

• List of medications
• Schedule next visit
• Prescription medications (bring list)
• Insurance card
• Understand instructions
• Questions
Supports Worksheet example

• Writing things down

<table>
<thead>
<tr>
<th>Problem that needs to be solved</th>
<th>Things I can do myself</th>
<th>Things I need help with</th>
<th>Who or what will be able to help me get this done</th>
</tr>
</thead>
<tbody>
<tr>
<td>Find out the date and time of the appointment</td>
<td>X</td>
<td></td>
<td>Look up the name the doctor's office gave me on line</td>
</tr>
<tr>
<td>Make sure I know where I'm going to and from</td>
<td>X</td>
<td></td>
<td>The address is on the card from the doctor's office</td>
</tr>
<tr>
<td>Look up phone number of bus company</td>
<td>X</td>
<td>X</td>
<td>The internet. I needed to ask some one I trust is good on the computer</td>
</tr>
<tr>
<td>Write down questions to ask bus company</td>
<td>X</td>
<td>X</td>
<td>I can help think of questions, but I need someone to write them down (maybe my mother)</td>
</tr>
<tr>
<td>Call the bus company</td>
<td>X</td>
<td>X</td>
<td>I can do it if everything is written down, but it might be helpful to have my mother there in case I need help</td>
</tr>
</tbody>
</table>

Notice how John does what he can to help himself, but then asks for help when he needs it. Notice also that he uses different kinds of help, including the internet, a family member, and a friend.
### Supports Worksheet

**Problem that needs to be solved:** I need to call my doctor

<table>
<thead>
<tr>
<th>List of things that need to be done</th>
<th>Things I can do myself</th>
<th>Things I need help with</th>
<th>Who or what will be able to help me get this done</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get the doctor's phone number</td>
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<tr>
<td>Write down my questions before I call</td>
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<tr>
<td>Call the doctor</td>
<td></td>
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<tr>
<td>Write down the answers to my questions</td>
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<td>Other thing to do:</td>
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</table>
Step three
Preparing
Preparing

• When do I need to start thinking about transition
  • Takes time to practice and gain independence
  • Plan with IEP and school (required to provide to age 22)
  • If traveling independently with a team or school program (have insurance card, know medications or take a list, contact numbers)
Preparing: Self-advocacy

• Become more in charge of own health care
  • First appointment
  • First prescription refill
  • Seeing provider alone
  • Asking questions to be sure understood
  • Pre assessment readiness for young adults and parents/caregivers

• As a parent how can I let go? Baby steps, give a chance
Assume Competency
Step four
Planning
Planning (occurs early)

- Age 18 – legal changes
  - Parents no longer automatically legal control
  - 18 yr olds consent to their own medical treatment
  - Needs to give written permission for PCP and office to involve others in medical information

- Who makes medical decisions?

- If young adult needs help with medical decisions – there are options
  - May need legal paperwork to continue to act as guardian
  - File paperwork to be guardian; medical advocate
  - Have to have that legally on record
  - Signed consent at Dr. office
Adult Medical Home

- Finding a new doctor
- Start with current office (may (should) suggest and help)
- Talk with people you know and who they liked – other parents, teachers, therapists, local agencies
- Healthcare plan directory
- Call the office to ask about – training insurance, hospital affiliation, do they take care of others with similar health issues
- It all takes time
- After the first visit – decide if feels like good fit
At school

- Going to College?
- Health services at college – bring updated Shared Plan of Care
- In college – need to be own advocate
- Meet with disability services center
- Explain special needs to teachers
- Good to have accommodation in place if need them
- Annual Bright Futures wellness visit
- Chronic condition management visit (Asthma, ADHD, depression)
Step five

Transferring
Transferring

- What info does my current doc need to send to my new doc?
- Shared Plan of Care
- Send copy of medical record and summary of any recommended treatment
- Should include a letter of introduction
- Would condition fact sheet help?
- Check to see if received records
Transferring

• Adult care different from pediatric care
• Main difference – you are only one communicating with new Dr office (unless release is signed)
• Adult approach should take place at both old and new office
• Expected to manage own appointments, medications, payments, insurance, refills on prescriptions
Questions to ask

• How to make and change appointments
• Transportation, parking, wheelchair access
• When to arrive, payment, what to bring with you
• Services available? SW, care coordinators
• After first visit – give feedback on how well it went, what could help you more.
IRB local pilot project:
Pediatric to adult medical home

- Project co-directors
  - Jill Rinehart, MD
  - Barbara Frankowski, MD
  - Allyson Bolduc, MD
  - VCHIP

- Adolescents/young adults vulnerable population
- High risk group--likely to drop out of health care system when most needed
Transferring

• Goal – transition process - seamless and welcoming for young adults.
• Population – Asthma, ADHD, Anxiety/Depression
• Four practices
• Pre-assessment readiness, medical summaries and plan of care, office champion, tracking adolescents, post visit assessments
“The transition period is a formidable time for a young adult in that they have to do some things for themselves that they have never had to do before…”

In conclusion

• Planning is key
• Takes time and energy
• Transition process begins earlier than one would think and progresses slowly
• Provider community and many other groups and agencies working hard to make transitions possible and easier
• More provider training is needed along with more accessibility
Resources

• Got Transition at http://www.gottransition.org

• Vermont Family Network at www.VFN.org

• Vermont Medical Society Resolution – Adopted 10/19/2013 –Improving Transition of Care

• Got Transition/Center for Health Care Transition Improvement which is a cooperative agreement between The Maternal and Child Health Bureau and the National Alliance to Advance Adolescent Health

• October, 2014 Pediatrics, “Transition Care for Children With Special Health Care Needs,” Alaina Davis, et.al
Resources, con’t.


• Green Mountain Self Advocates (list of resources to help with legal issues, health insurance issues, etc)

• State of Vermont Department of Health Children with Special Needs


• Sample Tools from Got Transitions; Florida Hats; PKU Clinic at U. of Washington, Seattle.
Tools

- My Health Passport (developed in Florida)
- Sample Medical Summary and Emergency Care Plan (Got Transitions)
- Transition Readiness for Youth and adults (Got Transitions)
- Check list for health care transition
- Pediatric vs Adult models of care how they differ (PKU clinic, University of Washington, Seattle)
- Sample Transfer letter and Transition Policy (Got Transitions)
- 10 Steps for successful health care transition (FloridaHats.org)
- Sample Plan of Care (Got Transitions)
My full name is: ________________________________
I like to be called: ____________________________
Date of birth: __/__/____
My primary care physician: _____________________
Physician’s phone number: _____________________

This passport has important information so you can better support me when I visit/Stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

My signature: ___________________________ Date completed: __/__/____

You can talk to this person about my health:
Phone number: ___________________________ Relationship: ___________________________

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

__________________________________________
__________________________________________
__________________________________________
My brief medical history: (Include other conditions e.g., visual impairment, hearing impairment, diabetes, epilepsy) past operations, illnesses, and other medical issues

My current medications are:

- 
- 
- 

When I take my medication, I prefer to take it: (e.g., with water, with food)

I am allergic to: (list medications or foods, e.g., penicillin, peanuts)

If I am in pain, I show it by: (also note if I have a low/high pain tolerance)

If I get upset or distressed, the best way you can help is by: (e.g., play my favorite music)
How I cope with medical procedures: (e.g. how I usually react to injections, IV’s, physical examinations, x-rays, oxygen therapy—also note procedures never experienced before or in recent years)

My mobility needs are: (e.g. whether I can transfer independently, devices I use, pressure relief needed)

When getting washed and dressed, you may assist me by:

When drinking, you may assist me by:

When eating, you may assist me by:
Sample Transition Readiness Assessment for Youth
Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date: ___________________________
Name: ___________________________
Date of Birth: ______________________

**Transition Importance and Confidence**

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

| How important is it to you to prepare for change to an adult doctor before age 22? |
|------------------|------------------|------------------|------------------|------------------|------------------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |

| How confident do you feel about your ability to prepare for change to an adult doctor? |
|------------------|------------------|------------------|------------------|------------------|------------------|
| 0 (not) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 (very) |

**My Health**

<table>
<thead>
<tr>
<th>My Health</th>
<th>Please check the box that applies to you right now.</th>
<th>Yes, I can do this</th>
<th>No, I need to learn</th>
<th>Someone needs to do this . . . Who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know my medical needs.</td>
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<td>I can explain my medical needs to others.</td>
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<tr>
<td>I know my symptoms including ones that I quickly need to see a doctor for.</td>
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<tr>
<td>I know what to do in case I have a medical emergency.</td>
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<tr>
<td>I know my own medicines, what they are for, and when I need to take them.</td>
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<tr>
<td>I know my allergies to medicines and medicines I should not take.</td>
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<tr>
<td>I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).</td>
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<tr>
<td>I understand how health care privacy changes at age 18 when legally an adult.</td>
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<tr>
<td>I can explain to others how my costs and beliefs affect my health care decisions and medical treatment.</td>
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**Using Health Care**

<table>
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<tr>
<th>Using Health Care</th>
<th>Please check the box that applies to you right now.</th>
<th>Yes, I can do this</th>
<th>No, I need to learn</th>
<th>Someone needs to do this . . . Who?</th>
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<tbody>
<tr>
<td>I know or I can find my doctor’s phone number.</td>
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<tr>
<td>I make my own doctor appointments.</td>
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<tr>
<td>Before a visit, I think about questions to ask.</td>
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<td>I have a way to get to my doctor’s office.</td>
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<td>I know to show up 15 minutes before the visit to check in.</td>
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<td>I know where to go to get medical care when the doctor’s office is closed.</td>
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<tr>
<td>I have a file at home for my medical information.</td>
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<td>I have a copy of my current plan of care.</td>
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<td>I know how to fill out medical forms.</td>
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<td>I know how to get referrals to other providers.</td>
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<td>I know where my pharmacy is and how to refill my medicines.</td>
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<tr>
<td>I know where to get blood work or x-rays if my doctor orders them.</td>
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<tr>
<td>I have a plan so I can keep my health insurance after 18 or older.</td>
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<tr>
<td>My family and I have discussed my ability to make my own health care decisions at age</td>
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</tbody>
</table>
Sample Transition Readiness Assessment for Parents/Caregivers
Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child's health care skills.

Date: ___________________________ Date of Birth: ___________________________

Transition Importance and Confidence
On a scale of 0 to 10, please circle the number that best describes how you feel right now.

**How important is it for your child to prepare for change to an adult doctor before age 22?**

<table>
<thead>
<tr>
<th>Score</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
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</tbody>
</table>

**How confident do you feel about your child's ability to prepare for change to an adult doctor?**

<table>
<thead>
<tr>
<th>Score</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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</tbody>
</table>

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### My Health

Please check the box that applies to your child right now.

- My child knows his/her medical needs.
- My child can explain his/her medical needs to others.
- My child knows his/her symptoms, including ones that he/she quickly needs to see a doctor for.
- My child knows what to do in an emergency.
- My child knows his/her own medications, where they are kept, and when he/she needs to take them.
- My child knows his/her allergies to medicines and medicines he/she should not take.
- My child carries important health information with him/her every day (e.g., insurance card, allergies, medications, emergency contact information, medical summary).
- My child knows he/she can call a doctor before I go in the waiting room.
- My child understands how health care privacy changes at age 16.
- My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.

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### Using Health Care

Please check the box that applies to your child right now.

- My child knows or can find his/her doctor’s phone number.
- My child makes his/her own doctor appointments.
- Before a visit, my child thinks about questions to ask.
- My child has a way to get to his/her doctor’s office.
- My child knows where to go to get medical care when the doctor’s office is closed.
- My child has a file at home for his/her medical information.
- My child has a copy of his/her current plan of care.
- My child knows how to fill out medical forms.
- My child knows how to get referrals to other providers.
- My child knows where his/her pharmacy is and how to refill his/her medications.
- My child knows where to get home care or x-rays if his/her doctor orders them.
- My child has a plan to keep his/her health insurance after age 18 or older.
- My child and I have discussed his/her ability to make his/her own health care decisions at age 18.
- My child and I have discussed a plan for supported decision-making, if needed.
# Health Care Transition Checklist

<table>
<thead>
<tr>
<th>Ages 12-14</th>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Develop knowledge of your health care needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Youth should be able to</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- describe medical condition(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- name medication(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- manage routine medical tasks</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explore appropriate work and volunteer opportunities</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Answer questions during a health care visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If eligible, sign up for Agency for Persons with Disabilities Med Waiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Continue self-advocacy skills, especially with health care providers and teachers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ages 15-17</th>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Take responsibility for making medical appointments and getting</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>prescriptions refilled</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Talk to medical providers during visits about age appropriate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>information regarding physical, emotional, and sexual development</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Begin thinking and talking about transition from pediatric to adult</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>health care providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discuss pediatrician’s discharge age and plan for transition and</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>transfer to adult care accordingly</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Keep a health record, including all medical paperwork</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Youth spend the majority of health care visits alone with the doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Check in annually with APD regarding the waiver waitlist status</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prior to 18th Birthday</th>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Finalize adult health care coverage</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reapply for Medicaid benefits</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reapply for SSI benefits (17 years and 11 months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Make decisions about Power of Attorney or other Guardianship options</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age 18+</th>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Transfer medical care from pediatric providers to adult providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reapply for Medicaid benefits</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Contact Vocational Rehabilitation to explore vocational assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explore living arrangements, education, and employment opportunities</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Make decisions regarding Power of Attorney or Guardianship</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Check in annually with APD regarding waiver waitlist status</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transfer medications to local pharmacy (if moving or going away to</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>school)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If going to college, learn about health care coverage and health</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>services provided on campus</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Pediatric vs. Adult care: How do they differ?

Health care for children is different than health care for adults. So, it makes sense that PKU clinic for children is different than PKU clinic for adults. This table describes some of the differences. Mark the item in the Adult Care column that you have questions about.

<table>
<thead>
<tr>
<th>Pediatric Care – Where you are now</th>
<th>Adult Care – Where you will be</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric PKU clinic</td>
<td>Adult PKU clinic</td>
</tr>
<tr>
<td>Parents are in charge</td>
<td>Care is self-directed</td>
</tr>
<tr>
<td>Care is monitored by parents and health care providers</td>
<td>Care is self-monitored and supported by health care providers</td>
</tr>
<tr>
<td>Appointments are scheduled</td>
<td>Adult must schedule own appointment</td>
</tr>
<tr>
<td>Support services are offered for financial and emotional issues</td>
<td>Adult must seek support services for financial and emotional issues</td>
</tr>
<tr>
<td>Parents are responsible for finances and payment</td>
<td>Adult is responsible for own finances and payment</td>
</tr>
<tr>
<td>Parents have insurance</td>
<td>Adult must have own insurance</td>
</tr>
<tr>
<td>Transportation provided by parents</td>
<td>Adult must provide own transportation</td>
</tr>
<tr>
<td>Parents request information about treatment</td>
<td>Must request own treatment information</td>
</tr>
<tr>
<td>Parents request information about outcome</td>
<td>Must request own information about outcome</td>
</tr>
<tr>
<td>Public health nurse services are available to help with day-to-day management</td>
<td>No public health nurse services are available</td>
</tr>
<tr>
<td>Pediatric specialty</td>
<td>Medicine Clinic</td>
</tr>
<tr>
<td>Education about reproduction concerns offered</td>
<td>Adult should make informed reproductive/contraceptive decisions</td>
</tr>
</tbody>
</table>

We don't expect you to have mastered all of these skills... yet.
Dear Adult Provider,

Name is an age year-old patient of our pediatric practice who will be transferring to your care on date of this year. His or her primary chronic condition is condition, and his or her secondary conditions are conditions. Name's related medications and specialists are outlined in the enclosed transfer package that includes his or her medical summary and emergency care plan, plan of care, and transition readiness assessment. Name acts as his or her own guardian, and is insured under insurance plan until age age.

I have had name as a patient since age and am very familiar with his or her health condition, medical history, and specialists. I would be happy to provide any consultation assistance to you during the initial phases of name's transition to adult health care. Please do not hesitate to contact me by phone or email if you have further questions.

Thank you very much for your willingness to assume the care of this young man or woman.

Sincerely,
[Pediatric Practice Name] is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.
10 Steps to Successful Health Care Transition

Success in the classroom, within the community and on the job requires that young people stay healthy. The best ways to stay healthy are to understand your health, participate in health care decision making, and receive age-appropriate care. Here are 10 ways to ensure a smooth transition from pediatric to adult health care for all teens and young adults, including those with disabilities or chronic health conditions.

1. **Start early!** Begin preparing for transition even when very young, like starting a health summary and talking about health needs.

2. **Focus on responsibility for health care.** Taking responsibility for health care should be based on age and abilities. Become more independent by learning the skills for managing health care, like scheduling appointments, arranging transportation, taking medications, filling prescriptions, and talking to doctors.

3. **Create a health summary.** Put important information about personal health in one place, including medications and plans for an emergency.

4. **Create a health care transition plan.** Work with your primary care provider to develop a written health care transition plan that includes future goals, services that will be needed, how they will be provided, and how they will be paid for.

5. **Maintain wellness.** Support good habits that will continue into adulthood! Talk about risky behaviors such as alcohol use and smoking as well as sexuality and relationships. You can ask to speak to your physician alone.

6. **If you have an Individualized Education Plan (IEP) or 504 Plan, include health care self-management activities in the plan.** Consider self-determination and advocacy skills, understanding personal health conditions and needs, and knowing how to access health care services.

7. **Know options for health insurance and public assistance programs in adulthood.** If you’re unsure about eligibility, it’s always best to go ahead and apply.

8. **Find adult providers.** If still in the care of pediatric providers, ask them to help identify and transfer to a primary care physician and specialists (including mental health professionals) who work with adults. Transfer of care typically occurs between ages 16 and 21.

9. **Know about legal rights and responsibilities.** That start at age 18! Learn about community services and supports for adults.

10. **Include health in other areas of transition.** Ask your primary care plan to provide documentation of medical conditions and special health care needs for other programs or agencies, as needed.

Visit www.FloridaHATS.org to find resources and services.
**Sample Plan of Care**

**Six Core Elements of Health Care Transition 2.0**

**Instructions:** This sample plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Motivational interviewing and strength-based counseling are key approaches in developing a collaborative process and shared decision-making. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be dynamic and updated regularly and sent to the new adult provider as part of the transfer package along with the latest transition readiness assessment, medical summary and emergency care plans, and, if needed, a condition fact sheet and legal documents.

<table>
<thead>
<tr>
<th>Name</th>
<th>Date of Birth</th>
<th>Primary Diagnosis</th>
<th>Secondary Diagnosis</th>
</tr>
</thead>
</table>

What matters most to you as you become an adult? How can learning more about your health condition and how to use health care support your goals?

<table>
<thead>
<tr>
<th>Prioritized Goals</th>
<th>Issues or Concerns</th>
<th>Actions</th>
<th>Person Responsible</th>
<th>Target Date</th>
<th>Date Complete</th>
</tr>
</thead>
</table>

Initial Date of Plan: ______________________

Last Updated: ______________________

Provider/Inservice Signature: ______________________

Clinician Signature: ______________________

Care Staff Contact: ______________________

Care Staff Phone: ______________________

*Get Transition®* Center for Health Care Transition Improvement, 01/2014 © Get Transition® is a program of The Jedidah Alliance to Advance Adolescent Health supported by DOJ/C51T95 RX/4078 by www.GetTransition.org
### Sample Medical Summary and Emergency Care Plan

**Six Core Elements of Health Care Transition 2.0**

This document should be shared with and carried by youth and families/caregivers.

<table>
<thead>
<tr>
<th>Date Completed:</th>
<th>Date Revised:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Contact Information

- **Name:**
- **DOB:**
- **Preferred Language:**
- **Parent (Caregiver):**
- **Relationship:**
- **Address:**
- **Cell #:**
- **Home #:**
- **Best Time to Reach:**
- **Email:**
- **Health Insurance/Plan:**
- **Emergency Contact:**
- **Relationship:**
- **Phone:**

#### Emergency Care Plan

- **Preferred Emergency Care Location:**

#### Common Emergency Presenting Problems

<table>
<thead>
<tr>
<th>Suggested Tests</th>
<th>Treatment Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Special Concerns for Disaster

- **Allergies and Procedures to be Avoided**

- **Allergies**
- **Reactions**

#### To be avoided

- **Medical Procedures:**
- **Medications:**

#### Diagnoses and Current Problems

<table>
<thead>
<tr>
<th>Problem</th>
<th>Details and Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Primary Diagnosis**
- **Secondary Diagnosis**

- **Behavioral**
- **Communication**
- **Feed & Swallowing**
- **Hearing/Vision**
- **Learning**
- **Orthopedic/Musculoskeletal**
- **Physical Anomalies**
- **Respiratory**
- **Skin**
- **Stomach/Fatigue**
- **Other**
## Sample Medical Summary and Emergency Care Plan
**Six Core Elements of Health Care Transition 2.0**

### Medications
<table>
<thead>
<tr>
<th>Medications</th>
<th>Date</th>
<th>Frequency</th>
<th>Medications</th>
<th>Date</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Health Care Providers
- **Provider:**
  - Primary and Specialty
  - Clinic or Hospital
  - Phone
  - Fax

### Prior Surgeries, Procedures, and Hospitalizations
<table>
<thead>
<tr>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
</tr>
</thead>
</table>

### Baseline
- **Baseline Vital Signs:**
  - HR
  - WT
  - RR
  - HR
  - BP

- **Baseline Neurological Status:**
- **Most Recent Labs and Radiology**

<table>
<thead>
<tr>
<th>Test</th>
<th>Date</th>
<th>Result</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>EEG</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>EKG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>X-ray</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C-Spine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MR/CT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Equipment, Appliances, and Assistive Technology
- **Gastrostomy**
- **Adhesive Seating**
- **Wheelchair**
- **Tracheostomy**
- **Communication Device**
- **Oxygen**
- **Suction**
- **Monitors**
- **Crutches**
- **Nebulizer**
- **Aptasia**
- **O2**
- **Walker**
- **Cardiac**
- **Insulin**
- **Other**
Sample Medical Summary and Emergency Care Plan
Six Core Elements of Health Care Transition 2.0

### School and Community Information

<table>
<thead>
<tr>
<th>Agency/School</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
</tbody>
</table>

Special information that the youth or family wants health care professionals to know

---

<table>
<thead>
<tr>
<th>Youth signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Parent/Caregiver</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Primary Care Provider Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Care Coordinator Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
</table>

Please attach the immunization record to this form.