SUPPORTING HEALTH CARE TRANSITION FROM ADOLESCENCE TO ADULTHOOD

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Maine Developmental Disabilities Council

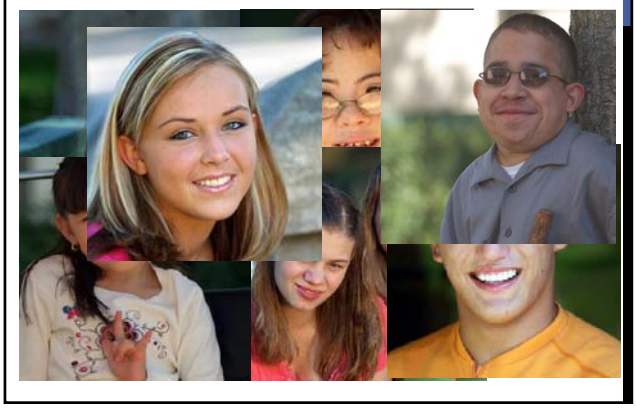
Maine Center for Disease Control and Prevention
An Office of the Department of Health and Human Services
Paul R. LePage, Governor Mary C. Mayhew, Commissioner

Transitioning Youth to Adult Health Care

Learning Objectives

- Transition Readiness
- Transition Planning
- Transfer of Care
- Transfer Completion

Transitioning Youth to Adult Health Care



Transitioning Youth to Adult Health Care

Transition Planning

Dr. Knotright

https://www.youtube.com/watch?v=W1CVs7j5x3U

Transitioning Youth to Adult Health Care

Leading the way in transitioning Youth with Special Health Care Needs (Ages 14-26) to adult Healthcare.

What is successful transition to adult healthcare?	Parent/Guardian	Child/Doctor	Adult Medical Provider
- An informed consumer - Locating a provider - Understanding their healthcare needs - Knowing how to work the system - Know what benefits are available to them - How to select a provider that meets their needs - Opportunity for choices	- Understanding your rights and what you no longer have access to in regards to your child's medical record - Knowing what your insurance covers for your adult child - Teach child how to be an informed consumer - Comfort level with medical provider - Support plan with medical provider "anticipatory guidance" - How to select a good fit	- Know where to transition to adult specialty care - List of place to refer for adult care - Provide anticipatory guidance list with tickler file - Reimbursement for extra work - Warm handshake to adult care - Understanding of health presentation of individuals with CYSHN - Medical provider relationship	- Need additional medical training to understand the complex needs of patients with complex medical issues - Comprehensive history coming with the patient - Accessible equipment and skills - What do they need?

Transitioning Youth to Adult Health Care

Transition

Why should providers prepare patients/families to transition to adult care?

https://www.youtube.com/watch?v=ECaao63W84I

Transitioning Youth to Adult Health Care

What Do We Know

Transitioning Youth to Adult Health Care

What Pediatricians Say…

- 2/3 Reported transition planning begins between 18-20 years for *all* patients
- 4/5 Perceived there was a lack of available adult primary care providers for CYSHCNs
- 4/5 Perceived there was a lack of available specialists

Fox et al. National Alliance to Advance Adolescent Health 2008 Fact Sheet n.6

Transitioning Youth to Adult Health Care

Adult Primary Care Providers Report

- Lack of training in childhood-onset and congenital disorders
- Fear that they are unable to meet patient's psychosocial needs
- Lack of social work and care coordinators in practices
- Limited knowledge about social (?community) resources
- Time / financial concerns

Pediatrics, Peter et al. (2009) Transition From Pediatric to Adult Care: Internists' Perspectives, Pediatrics;123;417

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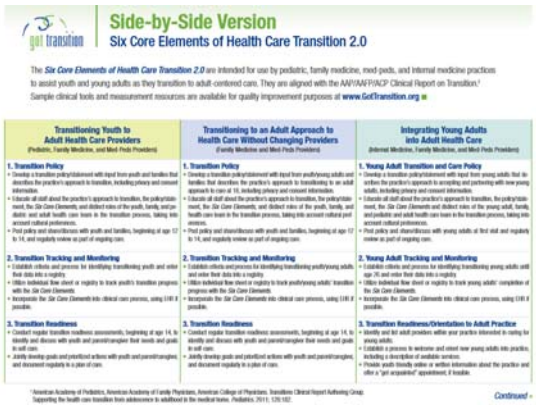
Phew – That Was In 2008…well…

- 2012 MDDC conducted Focus Groups of Pediatricians, Adult Practitioners, and specialists identified the following barriers in Maine
  - Concern about adult practitioners knowledge of disability
  - Cost of providing transition services
  - Need to fight for adult services
  - Fragmented care
  - Aging out of systems
  - The tendency for over medicating. (Psychiatrist) "What we see is that they age out, and then where do they go? That is when I get them. And they are on a ridiculous list of meds that we spend two years trying to trim down!"
  - Most referrals to adult medical specialists come from the parents – not the provider that served the individual in their youth.

Transitioning Youth to Adult Health Care

WHAT ADULT PRIMARY CARE PROVIDERS SAY THEY NEED / WANT….

- 95% Written transfer summary
- 95% "Support" from a specialist
- 84% Written information about condition impacting patient
- 91% Conversation with prior provider – AKA Warm handshake



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Side-by-Side Version

Six Core Elements of Health Care Transition 2.0

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Transition.[1] Sample clinical tools and measurement resources are available for quality improvement purposes at www.GotTransition.org

Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)	Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)	Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)
1. Transition Policy	**1. Transition Policy**	**1. Young Adult Transition and Care Policy**
2. Transition Tracking and Monitoring	**2. Transition Tracking and Monitoring**	**2. Young Adult Tracking and Monitoring**
3. Transition Readiness	**3. Transition Readiness**	**3. Transition Readiness/Orientation to Adult Practice**

Continued »

www.gottransition.org

Transitioning Youth to Adult Health Care

Transition Readiness

- Begins at age 14
- Conduct regular assessments
- Jointly develop goals
- Prioritize actions

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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 *Please check the box that applies to you right now.*	*Yes, I know this*	*I need to learn*	*Someone needs to do this… Who?*
I know my medical needs.	☐	☐	☐
I can explain my medical needs to others.	☐	☐	☐
I know my symptoms including ones that I quickly need to see a doctor for.	☐	☐	☐
I know what to do in case I have a medical emergency.	☐	☐	☐
I know my own medicines, what they are for, and when I need to take them.	☐	☐	☐
I know my allergies to medicines and medicines I should not take.	☐	☐	☐
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	☐	☐	☐
I understand how health care privacy changes at age 18 when legally an adult.	☐	☐	☐
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	☐	☐	☐
Using Health Care			
I know or I can find my doctor's phone number.	☐	☐	☐
I make my own doctor appointments.	☐	☐	☐
Before a visit, I think about questions to ask.	☐	☐	☐

www.gottransition.org

Transitioning Youth to Adult Health Care

Transition Planning

- Develop and update the plan of care
- Prepare youth and parent for adult approach to care
- Determine need for decision-making supports
- Plan with youth and family optimal time of transfer
- Obtain consent for release of medical information
- Assist youth in identifying an adult provider
- Provide linkages to insurance resources, self-care information and culturally appropriate community supports.

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Sample Individual Transition Flow Sheet
Six Core Elements of Health Care Transition 2.0

Patient Name: _____ Date of Birth: _____

Primary Diagnosis: _____ Transition Complexity: _____
Low, moderate, or high

Transition Policy

-Practice policy on transition discussed/shared with youth and parent caregiver _____
Date

Transition Readiness Assessment

-Conducted transition readiness assessment _____ _____ _____
Date Date Date

-Included transition goals and prioritized actions in plan of care _____ _____ _____
Date Date Date

Medical Summary and Emergency Plan

-Updated and Shared medical summary and emergency plan _____ _____ _____
Date Date Date

Adult Model of Care

-Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver (if needed, discussed plans for supported decision-making) _____
Date

-Timing of transfer discussed with youth and parent/caregiver _____
Date

-Selected Adult Provider

_____ _____ _____ _____ _____
Name Clinic Phone Fax First Appointment Completed

Transfer of Care

-Prepared transfer package including:
☐ Transfer letter, including effective of date of transfer of care to adult provider

www.gottransition.org

Transitioning Youth to Adult Health Care

Transition: Up Close

- Competency for independent decision making
- Insurance coverage
- Guardianship/Supported Decision Making
- Connection to community supports

Transitioning Youth to Adult Health Care

Ongoing At Every Visit

- Developmentally appropriate education / discussions on:
  - Sexuality / relationships
  - Nutrition and fitness
  - Substance use/abuse
  - Participation in health care decision making

Transitioning Youth to Adult Health Care

Implementing A Standard Of Care

- Transition Plans
  - Individualized to meet unique needs and goals of youth and family
  - Appropriate to youth's developmental level
  - Reviewed / updated regularly – changed when needed (may warrant increased # of visits or new assessments of abilities to successfully transition)

AAP Clinical Report 2011: Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

Transitioning Youth to Adult Health Care

Implementing A Standard Of Care

- **For all….**
  - Direct communication between pediatric and adult providers (primary and specialists)
  - Transfer of medical record (with "portable" summary that is also provided to patient and family)
  - "Pre-transfer" visit during the year before actual transfer

AAP Clinical Report 2011: Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

Transitioning Youth to Adult Health Care

Critical Steps

- Adaptive and Cognitive Functioning – if relevant -(Pediatric Sub-specialist / Schools / Referral to psychologist)
- Insurance coverage
- Confirm, connect and follow up with new provider

Transitioning Youth to Adult Health Care

Critical Questions For Families To Consider, When your child reach adulthood, what are your expectations for:

- Living arrangements
- Employment or post secondary education
- Recreational/leisure activities
- Behavioral health/health care
- Transportation
- Social skill activities
- Sexual expression
- Personal Hygiene and grooming
- Nutritional requirements
- Physical/cardiovascular expectations
- Spiritual life
- Guardianship
- Financial planning
- Health and Life Benefits
- Types of services needed

32nd Institute on Rehabilitation Issues (2007) Rehabilitation of Individuals with Autism Spectrum Disorders www.autism-info.org/2007_employment_&_ASD_report.pdf

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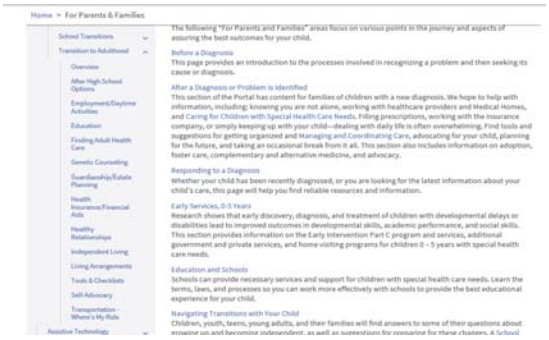
www.medicalhomeportal.org



Transitioning Youth to Adult Health Care

Checklist For Families

Download at www.medicalhomeportal.org

Transitioning Youth to Adult Health Care

College Bound? Some Tips To Practice Well Before Orientation

- Unstructured time
  - Unlike the typical college student's schedules many youth's schedules are highly structured so youth may struggle knowing how to fill the time up.
- Medications
  - Use only verbal/alarm prompts for medication
- Personal hygiene
- Know how to travel alone and use public transportation
- Appropriate coping strategies that can be utilized in most places
- Know how to do laundry
- Know how to manage money

College Support Program for Students with ASD (2011) Autism Training Center at Marshall University web source: http://mucollegesupport.blogspot.com/ accessed 4/27/2016

Transitioning Youth to Adult Health Care

Skills They Need To Transition

- Calling in a prescription refill
- Scheduling appointments
- Speaking up at the Doctor's Office
- Managing medication
- Make and keep follow-up visits
- Determine methods to track health progress
- Work with your doctor to set health goals
  - Personal Hygiene
  - Self Care (i.e. taking medications on schedule)
  - Preventing secondary conditions
  - Managing medications
  - What to do when there is an "emergency"
  - Wellness
  - Sexuality

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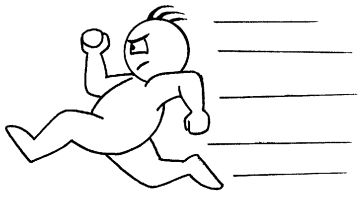


Transitioning Youth to Adult Health Care

Suggested Adult Service Application Timeline For Families

- Age 16 - Contact VR (Services will begin at age 18 but the transition plan and assessments should be done earlier)
- Age 17 - Identify and meet with adult health practitioner
- Age 17.5 - Apply for adult services through DHHS Office of Adults with Cognitive and Physical Disabilities (Even if the intent is to stay in children's services until the youth's 21 birthday.)
- Age 18 - If appropriate:
  - Apply for SSI.
  - Apply for MaineCare
    - Note: Even if individual was eligible for SSI and/or Mainecare as a child they must re-apply as an adult.
  - Consider guardianship or supportive decision making

Transitioning Youth to Adult Health Care

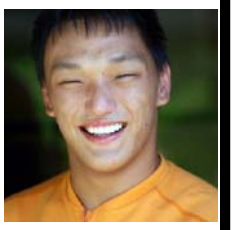
Adult Services

- Adult Developmental Services through the Office of Cognitive and Physical Disabilities
  - Waiver Services – Non Entitlement Program
  - Must be >2 standard deviations on a adaptive scale such as the Vineland to be eligible
  - All Waiver services are closed to a waitlist
- Vocational Rehabilitation
  - Eligibility guidelines
  - For many to access must also have the waiver for long term support
- Mental Health System

Transitioning Youth to Adult Health Care

Transfer of Care

- Confirm date of first adult visit
- Transfer young adult when condition is stable
- Complete transfer package, including final transition readiness assessment, plan of care
- Prepare letter of transfer



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Transfer Completion

- Contact young adult 3 to 6 months after last visit to confirm transfer
- Communicate with adult provider on transfer and offer consultation assistance, if needed
- Build ongoing and collaborative partnerships with adult primary and specialty care providers.

Transitioning Youth to Adult Health Care

Dr. Right

https://www.youtube.com/watch?v=6EJkOYmkxmE

Transitioning Youth to Adult Health Care

Quality Improvement, Make The Change

- Review (create) office policy on transition
- Discuss assigning roles within practice (resources – in community / within practice, create a data base
- Network with adult providers
- In services with community support agencies / schools

Transitioning Youth to Adult Health Care

EMMC Pediatric Primary Care - Transition Pilot

Questions?

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