

Healthcare Transition 101

Moving Youth from
Pediatric to Adult Care

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Overview

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What is “Healthcare Transition?”

- For youth with disabilities and special health care needs:
 - Getting medical care from providers trained to treat adults
 - Becoming knowledgeable about their health condition
 - Being responsible for carrying out their health tasks
 - Making good health care decisions

Is This Transition Really *That* Daunting?

- More than half of families of youth with special health care needs don't receive needed support for a smooth transition
- Pediatricians and internists believe that finding an adult medical home for young adults with childhood-onset conditions is difficult.

Getting Started

- Successful healthcare transition involves engagement and participation of:
 - Medical home team (physicians, nurse practitioners, care coordinators, etc.)
 - Family and other caregivers
 - YOUTH

Roles for Everyone!

- Medical home team:
 - Facilitates process that is:
 - Well planned and seamless
 - Patient and family centered
 - Should have an explicit policy that describes the approach to health care transition, including the age and process at which youth shift to an adult model of care

Roles for Everyone!

- Parents should:
 - Actively engage in the process
 - Address any anxieties or questions
 - Foster a team approach
 - Learn about any upcoming changes in health coverage
 - Move in and out of the decision making position as appropriate

Roles for Everyone!

- Youth should be able to:
 - Maximize their independence and primacy in the decision making process

Checklist (12-14)

- Describe how disability or health condition affects daily life
- Name medications (using their proper names) and the amount and times they are to be taken
- Answer at least one question during a health care visit
- Manage regular medical tasks at school
- Call primary care doctor's or specialist's office to make or change an appointment

Checklist (15-17)

- Explain the difference between a primary care doctor and a specialist
- Spend most of the time alone with the doctor during health care visits
- Answer most of the questions asked during a health care visit
- Tell doctors if they understand and agree with suggested medicines and treatments
- Reorder medications when supply is low and call doctor when a new prescription is needed

Checklist (18 and older)

- Manage all of their regular and routine medical tasks
- Explain the effects that getting older may have on their disability or health condition
- Know about medications that shouldn't be taken because of how they might interact with current medications
- Explain the new legal rights and responsibilities they gained once they turned 18 years old
- Have an idea of how long they can be covered under their parent's health insurance plan and what they need to do to maintain coverage

Privacy Matters

- Health care providers are required by law to respect the right to confidentiality of personal health information.
- They are not allowed to provide information to parents unless they have written permission to do so.

Privacy Matters

- For some young adults whose ability to make informed decisions is diminished, informal supports may be sufficient
 - Network of family and friends providing informal support and guidance
 - Must still operate within privacy laws
 - Can sign “release of information” forms so that family members will have access to medical information if the young adult so choose

Guardianship

- Young adults whose ability to make informed decisions is severely limited may need more formal supports
- Guardianship is:
 - Legal process that takes time and money and involves submitting a formal application through a court
 - Involves the courts formally declaring that your young adult is “incompetent” and unable to make certain decisions for themselves

Health Insurance

- Most private insurers allow young adults to remain on their parent's coverage until they turn 26 years old
- Health Services for Children with Special Needs
 - Coordinates all aspects of care for young adults with special health care needs
 - Young adults retain coverage up to age 25

Health Insurance

- Medicaid
 - Young adults who get Supplemental Security Income (SSI) benefits are automatically eligible for Medicaid
 - Young adults who might not otherwise be eligible, but have high medical expenses may also qualify

Health Insurance

- Medicaid
 - Qualifications change between ages 18 and 19
 - Children (age 0-18) use income at 300% FPL
 - Youth (age 19-20) use income at 200% FPL
 - Even if you were not financially eligible for Medicaid in the past, you may be eligible when you turn 19 because you can be considered as a “family of one,” for the purposes of determining financial eligibility

Resources and Acknowledgements

- “Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home”
Journal of the American Academy of Pediatrics
 - <http://pediatrics.aapublications.org/content/128/1/182.full.html>
- Institute for Child Health Policy at the University of Florida
 - <http://hctransitions.ichp.ufl.edu>

Resources and Acknowledgements

- “What You Need to Know: DC Medicaid and Alliance” – DC Department of Health Care Finance

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