Moving Into Adult Health Care

What Do Primary Health Care Providers Need to Know?

A guide for health care providers of young adults with and without disabilities

Connecticut Edition, 2012

This booklet was written by
CT-KASA
Connecticut Kids As Self Advocate

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Introduction

Why should health care providers care about transition?

Your role throughout the transition process is as a team leader and teacher who can help the youth and family in navigating the systems of care so they can successfully move into adult health care. Why is this important? The data tells us a lot about youth with disabilities and special health care needs:

- 90% of youth with special health care needs (YSHCN) will reach their 21st birthday and will need to find an adult health care provider.
- 45% of youth with disabilities lack access to a doctor who is familiar with their diagnosis.
- 30% of 18 to 24-year-olds don't have any way to pay for their medical care.
- Many youth can't find primary and specialty providers.
- Youth with disabilities have increased use of emergency system of care: 40% versus 25% of typical youth annually.
- There are fewer work opportunities and when youth with disabilities find jobs, they must be careful not to earn too much and lose Medicaid or SSI benefits.
- Youth with disabilities are three times more likely to live on incomes less than $15,000.

But for youth with disabilities or special health care needs, there is more than just data. We want to live productive, fun and independent lives!! We don't want to be treated like children yet we need help in learning how to find and use adult services and supports. We want to be seen as people first, not as a diagnosis or disability that might limit what we do. Mostly we just want to be prepared for adult independence so that we can focus on having a typical life, with the responsibilities and fun that others enjoy.

This booklet is about your role in helping youth with disabilities become healthy, independent and ready for adult life!

START EARLY!!

As soon as your patients are able to understand, you should explain to them why they are in the doctor's office and what will happen. Encourage them to bring their own questions that they may want to ask when they see you. Encourage their parents to help them think of questions, writing them down or bringing someone to help ask the questions at the visit.

There are many things a health care provider can do to make sure that a young child knows and understands his or her disability. Talk about the diagnosis and disability and give them the words to explain their disability to other children they meet. Focus on the things they can do, not the things they can't do.

Young children as well as teens can really benefit from straight talk. It is important to give your patient's disability the proper name, and explain what that means. This can better prepare your patient to seek appropriate health and support services later in life.

What is a Medical Home?

A medical home is not a place, but a way of delivering health care that is coordinated, patient and family centered and culturally appropriate. The medical home is also known as an approach to providing primary care that builds partnerships between individual patients, and their healthcare providers, and when appropriate, the patient's family. When health care is delivered through a medical home, young adults will have better access to health care, increased satisfaction with care, and improved health.

A key part of the medical home is care coordination. This includes assessing the needs of the young adult, planning the right services and supports, delivering those services and supports, and measuring how well these services and supports meet their needs and address their priorities. Building a sense of trust between young adults and the medical home, and responding to their needs in a timely and coordinated manner is essential.

Care coordination within a practice will:

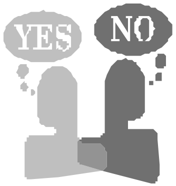
- Make it easier to access services
- Ensure consistent and coordinated care
- Provide needed support for young adults
- Improve health, developmental, educational, vocational, psychosocial and functional outcomes
- Maximize efficient and effective use of resources

At the Doctor's Office

There are many strategies that you can use during office visits that will help young adults be better prepared for transition.

Many young adults who do not have disabilities begin to see their doctor alone for at least part of a visit by the time they are 11 or 12 years of age. Many young adults with disabilities don't have the chance to see the doctor alone, even for part of a visit, and they don't learn how to manage their own health care or talk to the doctor. Make sure you spend some time during each appointment alone with your patients who have disabilities, so that they can talk freely without their parents. You will need to be prepared with appropriate communication strategies.

- Share information directly with young adults about their disabilities. You may have done this earlier with their parents, but it is important to have the conversation directly with the young adults.
- Encourage young adults to share with you their own information about their disabilities. This is an opportunity to talk more about their views, their goals, and their health care.
- If there are disagreements about the diagnosis, you need to discuss this as well, and help the young adult understand different perspectives. Encourage them to ask their own questions, and seek a second opinion if necessary.



Let Young Adults Take Charge of Their Health Care!

Teach us during your exams. When you are giving us an examination, give us the information about our physical status, special problems, and care needs so that we become familiar with our strengths, weaknesses, and needs.

Share with us a treatment plan and health history. We need to have all the right medical information from our childhood when we move into adult health care. This will help the young adult in case of emergency care as well. Also, this summary eliminates the need to send more lengthy medical records.

Speak directly to us, and let us answer your questions. In health care settings, the parent is frequently asked to speak for the young adult, even if that person can speak for him- or herself. If the patient is able to speak and answer, address him or her directly. Ask about his or her needs and preferences. This gives us an opportunity to assume some personal responsibility for our health and wellness.

Help us understand reports from other health providers. Sometimes we will have a conversation with a neurologist, geneticist, or other specialty. Your role is to help us understand the information and manage our health care.

Help us learn to explain our diagnosis or disability to others.

Give us information on resources and supports. Provide resource lists, referral sources links to other community services.

Check in with us from time to time about our life plans and how we feel about our disability. As we get older and become more independent, we may think differently about our health needs and life choices. We may need help in making choices to support our priorities in life. For example, if we want to go on vacation with friends or move away from our home as adults, we need help thinking about what health care and supports we might need. Take a holistic perspective that combines typical health and development issues with those specific to the person.

Help us learn how to plan for our care as adults.

Discuss sexuality, cycles and medication like birth control to help us manage our hormonal changes.

Don't blame every health issue on our disability. Teach us about basic health care and prevention and help us recognize that some of our health care is just like everyone else's.

Learn to trust that we can be good reporters of our health information.

Teach your office staff to work with us as well. Ask them to give us give clear instructions and give any forms directly to us. Ask them to help us schedule our own appointments, check in at the beginning of an appointment, and manage our insurance paperwork.

Help us plan for emergencies. Make sure we have a completed emergency form, and know what to do if we have a medical emergency.

Help Young Adults Learn What To Do If They Disagree with the Doctor

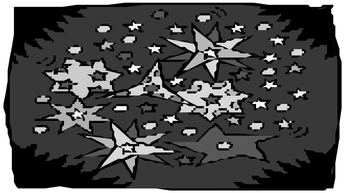
Disagreement over treatment plans and choices can be a very difficult situation.

Encourage young adults to let you know if they are confused or do not agree. They need to learn to make good health care choices.

Encourage them to seek a second opinion if needed. Encourage them to see another doctor who may specialize in the treatment of their symptoms or diagnosis, or another primary care doctor. Many insurance plans cover second opinions.

Seek help from the care coordinator in your medical home. If you are providing care in a medical home, then review all the relevant information about a care plan and help the young adult decide what to do next. This might include having a meeting or phone call with other providers to discuss options, or finding a provider for a second opinion. It is important to let the young adult talk about the challenges when they receive different information and treatment plans from different providers.

The most important thing to remember is that young adults have to learn to make informed decisions about their care.
This means getting as much information as possible before making a decision.



Moving Into Adult Health Care

As your young adult patients approach age 18, you may need to help them find an adult health care provider who understands their unique health needs. Talk with your patients about their needs and preferences.   Some young adults may choose to receive medical care from the physicians who treat their parents. This may work well for some patients. Other young adults may want a referral from their pediatrician to an adult health care provider.

There are many things for your patients to consider-accessibility of the office, knowledge of their disability, other patients with similar disabilities treated by this physician, and whether or not they will accept their insurance.

In most cases, there will need to be an initial discussion of special health care needs in addition to the transfer of records that will routinely occur. You can help prepare your young adult patients with questions to ask and a medical summary.

Quick Links to Health Care Transition Resources

Connecticut Department of Public Health
Youth with Special Health Care Needs

- **http://www.ct.gov/dph/cwp/view.asp?a=3138&q=432684**

Connecticut Kids As Self Advocates (CT KASA)

- **http://www.ctkasa.org/**

Got Transition? National Health Care Transition Center

- **http://www.gottransition.org/**

Health Care Transitions: The Institute for Child Health Policy at the University of Florida

- **http://hctransitions.ichp.ufl.edu/hct-promo/**

Healthy and Ready to Work National Resource Center

- **http://www.syntiro.org/hrtw/**

National Center for Medical Home Implementation - Transitions

- **http://www.medicalhomeinfo.org/how/care_delivery/transitions.aspx**

United Way of Connecticut 2-1-1 Infoline

- **http://infoline.org**

NOTES

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