Webinar Series: Health Care Transition & Title V Care Coordination Initiatives

A five-part Webinar Series featuring examples of best practices among state Title V agencies, tools and resources, and problem-solving strategies.

Session 3 · Transfer to Adult Care

- Identifying willing adult primary and specialty providers
- Sequencing plans for transferring young adults with multiple providers
- Identifying ways to support adult practices (consultation, care coordination)
- Preparing transfer package and communicating with pediatric and adult practices

Click here to view webinar recording on YouTube

MATERIALS INCLUDE:
- Care Coordination Webinar 3 Slides: Transfer to Adult Care
- Got Transition Materials
- Kentucky Transition Materials
- Coordinating Center Transition Materials

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Health Care Transition & Title V Care Coordination Initiatives: Webinar Series

Webinar # 3 | April 26, 2018

TRANSFER TO ADULT CARE

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Lee Gordon, MPA
Kentucky Commission for Children with Special Health Care Needs

Kathy Rivers, MD
The Coordinating Center (Maryland)

Peggy McManus, MHS
Got Transition
The National Alliance to Advance Adolescent Health
Disclosures and Funding Source

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Got Transition’s Webinar Series Goals

• Support state Title V implementation and measurement of health care transition (HCT) in care coordination programs

• Guide care coordination improvements by sequentially building on the evidence-informed Six Core Elements

• Share promising practices from state Title V-supported care coordination programs (CC)

• 5-session webinar series on HCT and care coordination

• The webinars and handouts will be available following each session at www.gottransition.org
Webinar #3
Objectives

At the conclusion of Webinar 3, attendees will be able to...

- Identify ways for identifying adult primary and specialty providers
- Understand an adult model of care & Got Transition resources
- Understand contents of transfer package to send to adult provider
- Identify ways to communicate with and support adult practices (e.g., care coordination support)
- Learn how KY and MD CC programs plan and support transfer to adult care
Webinar #3 Handouts

1. Webinar #3 Slides
2. Got Transition’s Turning 18, Guardianship and Alternative for Decision-making Supports; Questions to Ask Your Doctor About HCT; YA Quiz
3. Kentucky’s transition policy & 18 year old birthday letter (parents & youth)
4. Coordinating Center’s Adult Provider Transfer Package, Adult Outreach Package, and Delineation of Roles Handout
Webinar #1
Review: Starting a Transition Improvement Process Using the Six Core Elements

• HCT clinical foundations: AAP/AAFP/ACP Clinical Report & Six Core Elements
• HCT performance measurement options
• Title V Care Coordination baseline results from Current Assessment of HCT
• Starting a HCT pilot using Quality Improvement and the Core Elements Processes; writing an aim statement
Webinar #2
Review: Transition Preparation

- Review of Six Core Elements: Transition Policy, Tracking, Readiness Assessment, Planning
- Options for Customizing HCT Tools/ACP HCT efforts
- DC’s Parent Navigator Program at Children’s National Health System’s customization and use of Six Core Elements
Transfer Success: Consumer, Provider, Researcher Perspectives

• “An easy transfer is associated with feeling ready and considering that coordination between teams is good.” (Suris et al, 2016)

• Success is:
  ➢ Patient attending scheduled visits to adult care & not lost to follow-up
  ➢ Patient building trusting relationship with adult provider
  ➢ Patient receiving continued attention for self-management
  ➢ Patient satisfied with transfer process (Sattoe et al, 2016)
Six Core Elements: Transfer of Care

- Plan with youth/family for optimal time for transfer
- Assist in identifying adult provider
- Complete transfer package and communicate with new adult provider
- Transfer when YA’s condition is stable
- Confirm pediatric provider’s responsibility for care until YA is seen in adult practice
Adult Model of Care

- Preparing for adult model of care includes meeting with HCP alone, practicing independent self-care skills
- At age 18, youth becomes legal adult. Medical information cannot be shared unless permission given
- See: Got Transition Handouts: Turning 18, Guardianship & Alternatives for Decision-making Support, Questions to Ask Your Doctor about HCT, YA Quiz)
Adult Model of Care

• Patient-centered
• Care is self-directed
• Very limited resources for care coordination
• Role of adult primary care and specialty doctors often different than in pediatrics

“Leaving Never Never Land”
Transfer Package

- Transfer letter
- Final transition readiness assessment
- Plan of care, including transition goals and pending actions
- Updated medical summary and emergency care plan
- Guardianship or health proxy documents, if needed
- Condition fact sheet, if needed
- Evidence of communication with adult provider about transfer
The Kentucky Office for Children with Special Health Care Needs

Karen Rundall, RN, MSN, CCM
Division Director - Clinical & Augmentative Services

Lee Gordon, MPA
Transition Administrator
Commission for Children with Special Health Care Needs
Regional Offices
Satellite Clinics
Title V Care Coordination

• In FY 2017 the CCSHCN provided 78,302 services to 9,148 unduplicated patients through specialty medical clinic programs and augmentative programs.

• Staff mix includes Registered Nurses, Social Workers, Administrative Support staff, Audiologists, Speech Language Pathologists, Dieticians and Family Support Parents in our larger offices.

• Registered nurses, social workers, support parents and providers collaborate with patients and families to create a plan of care.

• The multidisciplinary team at the CCSHCN assists with linking the patient/family with needed medical and social resources to assist with transition as well as overcoming financial, language and cultural barriers.
Specialty Medical Clinic Programs

- Autism Spectrum Disorder
- Cerebral Palsy
- Cleft lip & Palate
- Craniofacial Anomalies
- Ophthalmology
- Cardiology
- Neurology
- Orthopedics
- Otology
- Audiology
- Therapy Services

- The specialty clinics included currently fill gaps in medical care that exist in the regions where they are held.

- CCSHCN contracts with sub-specialists from University of Kentucky and University of Louisville who travel to our regional offices and provide clinical services to children enrolled in the CCSHCN program.

- Programs can be added if a gap in service is demonstrated and a provider is available.

- Programs can be removed if services become available in a region and a gap no longer exists.
Six Core Elements of Health Care Transition - KY

1. Transition Policy - Yes
   - CCSHCN developed a Transition policy utilizing the transition policy example on the Got Transition website.
   - Staff were informed about the policy and their role in the transition process.
   - The policy is posted in all 11 of our CCSHCN clinics.
   - The policy is mailed with a transition letter to all 14, 16 & 18 year old patients on their birthday.

2. Registry - Yes
   - CCSHCN uses an Electronic Health Record called CUP that all patient information is entered in.

3. Transition Readiness Assessment - Yes
   - The CCSHCN Transition Checklist is in CUP.
   - Staff enter transition progress notes to support the transition checklist as they meet with youth and families during the clinical process.
Six Core Elements of Health Care Transition - KY

4. Transition Planning - Yes
   • The CCSHCN Transition Checklist focuses on age appropriate transition questions for ages: (0-4, 5-11, 12-14, 15-17 & 18-21).
   • Prior to age 18, youth are informed about: The need to choose an adult health care provider when he/she turns 18; Be familiar with health insurance and how it works– i.e. insurance plans, deductibles, co-pays, etc.; and informed about the importance of organizing and keeping medical records and receipts.

5. Transfer of Care - Yes
   • Staff develop a portable medical summary that is given to patients to use upon transfer to an adult provider.
   • Staff inform patients about the FEMA emergency preparedness brochure titled “Preparing Makes Sense for People with Disabilities https://www.fema.gov/media-library/assets/documents/90360

6. Transfer Completion – Yes
   • Clinic surveys are completed by patients/family members during the clinic process.
   • Transition phone surveys are attempted with each CCSHCN patient after the patient turns 21 years old and ages out of the CCSHCN.
Transition Standard: Transition to Adulthood

**Standard**: The CCSHCN will provide high quality transition support services to CYSHCN to assist them to make a successful transition to all aspects of adult life including health care, education, employment and independence to the full extent of their potential.

**Activities:**
- Information and patient education
- Linkage to needed services
- Facilitating access to service providers
- Advocacy and youth empowerment opportunities
- Support and encouragement
- Care Coordinators services for CYSHCN during transition to adult health care
- Youth Advisory Council

**Performance Evidence:**
- Patients and their families will attend clinics and be asked appropriate age group transition questions from the CCSHCN Transition Checklist in CUP. Patient and their family’s responses to the transition checklist questions will be documented in the medical record.
- Patient follow up on referral services will be documented in the medical record.
- All transition support services will be documented in the patient record.
- Parents will participate in satisfaction surveys.
Age Specific Information Timetable with Focus on Transition to Adult Care

The CCSHCN Transition Checklist focuses on age appropriate transition questions for ages: (0-4, 5-11, 12-14, 15-17 & 18-21). Beginning at age 12 questions are directed at the patient. Below are some questions targeted at preparing the youth to transition to adult health care.

**Health 12 – 14**
I understand my diagnosis and can explain it.
I tell the doctor how I am doing and answer questions.
I take my medicine with or without supervision.

**Health 15 – 17**
I talk with my doctor/nurse/social worker about the need to choose an adult health care provider when I turn 18.
I am familiar with health insurance and how it works—i.e. insurance plans, deductibles, co-pays, etc.
I understand the importance of organizing and keeping my medical records and receipts.

**Health 18 – 21**
I have plans for adult health care providers (Primary Care, Specialty, Dental, DME, Pharmacy, Therapy and Mental Health) and have made initial appointments to establish care with them or are already seeing them.
Recruitment of Physicians

Types of Providers Available:
• Family Medicine Practices
• Parent’s adult PCP
• Federally Qualified Health Centers (FQHC)
• Medical Center Adult Health Care Clinics
• Adult Primary Care Provider

Process:
• CCSHCN staff perform regular outreach to area provider offices and FQHCs to provide information regarding transitioning youth with special health care need to adult care and the care coordination and assistance that can be provided to support until age 21 years.
• CCSHCN staff attend community partner meetings and community health fairs to learn about new area providers, stay in touch with current community providers and build relationships.
Portable Medical Summary

• Child’s Name
• Child’s Nickname
• DOB
• Health insurance
• Legal guardian
• Diagnosis
• Clinical summary
• Emergency Plan
• Allergies
• Medications

• Specialists
• Baseline Vitals (includes HT/WT)
• Problem List/Recommended Actions
• To be avoided
• Surgeries/procedures
• Labs/Diagnostics
• Equipment/Appliance/Assistive Technology provided
• Medical monitors provided
• School/Community Information
## Portable Medical Summary

<table>
<thead>
<tr>
<th>Parent/Caregiver Signature</th>
<th>Date</th>
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<table>
<thead>
<tr>
<th>Primary Care Provider Signature</th>
<th>Print Name</th>
<th>Contact Into</th>
<th>Date</th>
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<tr>
<th>Care Coordinator Signature</th>
<th><strong>Special Circumstances/Comment/Family/Youth wants us to know:</strong></th>
<th>Contact Into</th>
<th>Date</th>
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Lessons Learned

• Call the physician’s practice for a good day and time to visit
• Try to connect with the physician’s nurse
• Try to establish a relationship with one contact person in the office
Introductory Remarks

Jed Miller, MD, MPH
Maryland Title V CSHCN Director
Health Care Transition & Title V Care Coordination Initiative
Transfer to Adult Care

Identifying and Partnering with Adult Health Care Providers at The Coordinating Center

Kathy Rivers MD
Got Transition Webinar #3
April 26, 2018
3 – 4 pm
The Coordinating Center...

The mission of The Coordinating Center is to partner with people of all ages and abilities and those who support them in the community to achieve their aspirations for independence, health and meaningful community life.
Rare and Expensive Case Management (REM) and Model Waiver Programs

- **REM**
  - Provides integrated coordination of services for people with specialized health care needs that are defined as rare in occurrence and expensive to treat
  - Serves 4,200 individuals
  - 75% younger than 18

- **Model Waiver**
  - 200 children with complex medical needs at risk for long-term hospitalization without necessary in-home services
  - Under 22, not eligible for other Medicaid programs

- Funded by Maryland Medicaid

“One of the greatest challenges we face is the need to prepare youth and families for transition to adulthood, including health care transition.”
Transition Connection Initiative (TCI)

Funded by a systems development grant from the MD Dept of Health’s Office of Genetics and People with Special Health Care Needs (Title V)

Goal: Improve HCT for YSHCN, their families and their providers

- Implement the 6 Core Elements model of HCT at The Coordinating Center
- Customize HCT tools for the REM/MW population
- Care coordination model with staff training and support
- Provider outreach, education, and support
- Recruitment of adult primary care providers
TCI Baseline Client Assessment

• Only 21% of respondents received assistance identifying a new adult PCP
• Most transfers occurred between 18 and 21
• 1/3 of clients over age 22 had pediatric PCPs
• Families want advance notice about HCT policies and to be part of transfer planning
TCI Provider Surveys

• Providers want training, communication, support and resources
  • childhood-onset complex chronic illness management
  • adult health challenges facing long-term survivors

• Pediatricians
  • List of adult PCP’s willing to accept YSHCN

• Adult Providers
  • More communication from pediatric providers to improve transfer and ongoing care
  • A plan of care for the next year
  • Information about adult disability resources
REM Adult Provider Survey Comments

• “Why do I need a policy for integration of YA with SHCN? I accept new adult patients all the time.”

• “The young adult is an unreliable historian and comes with no or insufficient medical records.”

• “I need (but never get) a concise medical summary and a plan of care for the next year. Then I could implement the plan while I get to know the patient instead of having to start from scratch at the first visit.”

• “No one at Peds talked to the family about advance directives and the discussion is clearly needed, but if I raise the issue early in our relationship I look like the grim reaper.”

• “The structure of my clinic doesn’t support the extra time these patients need. Also I’m willing to see them but my staff gets upset about time spent, extra paperwork, office schedule disrupted and extra care needed.”
TCI Action Plan for Adult Provider Recruitment

• Identification
• Engagement
• Education
• Support
• Increase capacity
REM Program Examples - Identify Adult Providers

**Who** – starting “the list”
- Internal database of adult PCPs already seeing REM clients
  - Existing connection with ASHCN
  - Add other providers in their office/network
  - Providers accepting new patients
- Parents’ adult PCPs
- Pediatrician’s referral list

- Med-Peds!
- Geriatricians
- Educational outreach/CME attendees
- AAFP, ACP
- Networking contacts
- The Office Manager
- “But I don’t want my name on a list!”
Adult Provider Engagement

**What** – make a connection
- Outreach
- HCT educational event
- Provider packet

**Where**
- In person
  - Provider office
  - Group home
  - Provider event
- Remote – call, email, ECHO

**When**
- Whenever it is most convenient for the adult PCP
  - After office hours

**How**
- Survey
- Phone call
- Email
- Fax
- Letter
- Website
- Social media
Adult PCP HCT Education

• Outreach - Meet with PCPs and their staff to discuss
  • The importance of HCT/transfer for YSHCN
  • The 6 Core Elements Approach to HCT
  • Current office HCT policy
  • Practice issues with and needs for HCT planning
  • Consider adding HCT to Medical Home efforts

• Presentations
  • Staff meetings
  • CME events
  • Partner with provider organizations (AAP, ACP, AAFP); sponsor joint events
Adult Provider Training Requests

- Adult consequences of pediatric-onset chronic diseases
  - Care of Adults with Chronic Childhood Conditions: A Practical Guide by Pilapil, M et al. (Eds) Springer Nov 2016 (436 pp) [http://www.springer.com/978-3-319-43825-2](http://www.springer.com/978-3-319-43825-2)
    - Chapter 1 Facilitating the Transition from Pediatric-Oriented to Adult-Oriented Primary Care by Patience H. White and Margaret McManus
- Management of neurodevelopmental disorders
- Mental/behavioral health disorders management
- Medical technology needs
- YA development, complicated by chronic disease
REM Program Adult Provider Support

• Care coordination assistance
  • REM/MW youth and families ready by age 22 for adult model of care
  • Client support for integration into adult practice
  • Adult subspecialty provider resources
  • Local/state/national adult disability resources

• Transfer packages
  • Most recent transition readiness assessment
  • Medical summary and emergency care plan
  • Care management plan
  • Plan of care for the next year
  • Legal decision-making supports documentation, if needed

• Link to pediatric provider for information/consultation
Increase Number of Adult Providers Caring for YASHCN

- Identify, engage, educate, support to increase system capacity - grow “the list”
  - Obtain feedback (client, provider) to inform program change
  - Collect data performance measures
  - Collaborate with state transition leaders for systems change
  - Share resources
  - Start early - HCT education in medical curriculum
Questions?

- About identifying adult providers?
- About preparing a transfer package?
- About ways to support adult practices in integrating young adults into their practice?
- About KY’s approach?
- About MD’s approach?
Upcoming Title V Care Coordination Webinars

Integration into Adult Care
May 31, 3-4 pm ET

Youth, Young Adult, & Parent Engagement
June 28, 3-4 pm ET

To register, please visit Got Transition's website under Webinars (www.gottransition.org/webinars)
Thank You!

WEBSITE
www.gottransition.org
See link to new transition news and articles and download the *Six Core Elements 2.0* packages to start making HCT quality improvements in your practice

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FACEBOOK PAGE
HealthCareTransition

TWITTER
@gottransition2
Turning 18: What it Means for Your Health

Turning 18 may not make you feel any different, but legally, this means you are an adult.

What does this mean?
- After you turn 18, your doctor talks to you, not your parents, about your health.
- Your health information and medical records are private (or confidential) and can’t be shared unless you give the OK.
- It is up to you to make decisions for your own health care, although you can always ask others for help.

Things to Know
- The confidentiality between you and your doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA.
- This law gives privacy rights to minors (people who are under age 18) for reproductive and sexual health, mental health, and substance abuse services. Check your state’s minor consent laws for more information.

What needs to be done?
- If you want to share medical information with others, your doctor will ask you to fill out a form that allows them to see your medical record.
- If you need help making decisions, talk to your family, your support team, and your doctor about who needs to be involved and what you need to do to make sure they can be a part of the conversations.

Additional Resources
- If you know you need extra support managing your health or making decisions, the National Resource Center for Supported Decision-Making has information to connect you with resources in your state.
Guardianship and Alternatives for Decision-Making Support
Written by: Got Transition Staff with support from Tina Campanella, Quality Trust for Individuals with Disabilities

HEALTH CARE TRANSITION AND DECISION-MAKING
For a youth or young adult who has intellectual disabilities, his or her health care transition often raises questions for health care providers and families about guardianship. This brief provides a high level look at guardianship and other decision-making supports as well as resources that will provide more in-depth information.

Guardianship Issues

Reaching the age of 18 — Opportunities and Challenges for Young Adults with Disabilities
Reaching the age of majority (18 years, in most states and jurisdictions) means, under state law, an individual is no longer a "minor." As such, the person has the right and responsibility to make certain legal choices that adults make. For some young adults with intellectual disabilities, this may be an exciting opportunity for increased independence. However, there may also be family concerns about how to best support that person’s self-determination in making life decisions such as for health care or in financial management.

This brief provides a broad outline of decision-making support options, both informal and legal, that may assist a young adult with an intellectual disability. States and jurisdictions may have different laws and options. Each state defines the categories and rules for guardianship in its laws. It is important to know all of the options before deciding which one to pursue since every young person has a unique situation and individual needs for support.

Decision-Making — A Skill that Requires Practice and a Variety of Experiences
Decision-making is a learned skill. Children and youth who have support and experience choosing what to wear, eat, who to socialize with etc., will approach adulthood having exercised this skill early on. Ongoing decision-making experiences lead to confidence and a self-awareness that "I am able make decisions that direct my life." When a youth or young adult is denied the opportunity to make decisions or to participate in a shared decision-making process, this lack of skill building may lead to a perceived "incapacity" either by the family or by the young adult him/herself.

Despite having opportunities for decision-making early in life, not all young adults with intellectual disability are able to make all decisions especially those choices with more far reaching impact on their lives. In these situations, the right amount of support at the right time can help build on early decision making experiences.

The Right Support at the Right Time
"Informal" support from a young adult's circle of friends and family may be enough to help the young adult talk over life decisions while maintaining the young adult's unrestricted self-determination. When it comes to issues such as health care decisions or money management, there may be legal options available to assist the young person to "share" decision responsibilities with a trusted friend or family member. Joint or trust fund accounts, financial powers of attorney, health care durable powers of attorney, conservatorships or "waivers of confidentiality" for individual health care issues are options that can support a young person's decision making while providing timely guidance, as needed, for important issues.
Guardianship — More Restrictive Option with Alternatives

Guardianship is a formal, legal process in which a court is requested to assume responsibility for a person as a "ward" and then may appoint an "agent" to act as guardian. The guardian may or may not be a parent or family member, and the guardian's authority is determined by the judge's order or state law. The guardian may have certain responsibilities to the court i.e. submit written reports, attend additional hearings as needed, and maintain standards that preserve the ward's decision-making process, as much as possible.

Some families pursue guardianship because they believe or have been told that it's the only legal answer to concerns they may have about their young adult's ability to handle money or access and stay connected to adult or health care services. While some form of legally arranged guidance may be called for, full guardianship may not be the only option. There may be forms of guardianship that can provide temporary or specific decision-making support while not completely denying the young adult's participation in that decision. When it comes to determining what is the best option, the "least restrictive" ones may best support and promote the young adult’s decision-making skills and rights.

Each state will have their own definition of guardianship options as well as laws to govern them and every young person has a unique situation and needs. In researching options, families may want to consider availability and appropriateness of options for "emergency," "temporary," "limited,“ or "provisional" guardianship, 90-day health care guardians, or conservators. Sometimes a combination of different and least restrictive options may be required in order to provide the best assistance.

Guiding Questions to Ask in Considering Decision-Making Support Options

In summary, in considering what the right decision making support for young adults may be, here are some key questions families may ask:
1. What kind of decision is being made?
2. Has the person made a decision like this before?
3. Has the person been assisted to understand the risks and benefits?
4. How big is the impact of this decision in the person's life?
5. How long would the person live with the decision?
6. How hard would it be to undo?
7. Most important: What is the least restrictive level of support that might work?

PROTECTING EVERY YOUNG ADULT PATIENTS RIGHT TO PRIVACY AND CONSENT

Health care providers, especially those accepting a young adult with intellectual disability into their primary care practices, must protect every patient’s right to privacy and consent. Along with past medical records and health-related information, the health care provider in this situation will need accurate information regarding the individual’s independent decision-making status and the names of anyone who has been appointed or identified to support decisions on the young adult’s behalf.

RESOURCES FOR MORE INFORMATION ON GUARDIANSHIP AND DECISION-MAKING ALTERNATIVES:

FOR PARENTS:

QUESTIONS TO ASK YOUR CHILD’S DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE

DURING YOUR CHILD’S ADOLESCENT YEARS:

☐ When does my child start to meet with you on their own for part of the visit to become more independent when it comes to their own health and health care?

☐ What does my child need to learn to get ready for adult health care? Do you have a checklist of self-care skills that my child needs to learn?

☐ Can I work with you to prepare a Medical Summary and Emergency Care Plan for my child?

☐ Before my child turns 18 and becomes a legal adult, what information about privacy and consent do we need to learn about? If my child needs help with making health decisions, where can I get information about this?

☐ At what age does my child need to change to a new doctor for adult health care?

☐ Do you have any suggestions of adult doctors for my child to transfer to?

BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:

☐ Do you take my health insurance?

☐ Where is your office located? Is there parking or is it near a metro/bus stop?

☐ What are your office hours, and do you have walk-in times?

☐ What is your policy about making and cancelling appointments?

☐ If needed, can the new adult doctor help find adult specialty doctors?

BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:

☐ Did you receive my medical summary from the pediatric doctor? (If not, call the pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)

☐ What should I bring to the first visit?

Please visit www.gottransition.org for more information.
FOR YOUTH & YOUNG ADULTS:

QUESTIONS TO ASK YOUR DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE

DURING YOUR ADOLESCENT YEARS:

☐ When do I start to meet with you on my own for part of the visit to become more independent when it comes to my own health and health care?

☐ What do I need to learn to get ready for adult health care? Do you have a checklist of self-care skills that I need to learn?

☐ Can I work with you to prepare a Medical Summary and Emergency Care Plan?

☐ When I turn 18, what information about privacy and consent do I need to know about? If I need help with making health decisions, where can I get information about this?

☐ At what age do I need to change to a new doctor for adult health care?

☐ Do you have any suggestions of adult doctors to transfer to?

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Please visit www.gottransition.org for more information.
Are you ready to transition to adult health care?

Take the quiz here:

bit.do/HCTquiz

got transition
The Commission for Children with Special Health Care Needs (CCSHCN) 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 patients take full responsibility for decision-making. This means that we will spend time during the clinic visit talking more with the teen to assist him/her in setting health priorities and supporting her/him in becoming more independent with his/her own health care. The CCSHCN uses a transition checklist that has age appropriate developmental milestone questions as a guide when speaking with teens about appropriate health care transition topics.

At age 18, a youth legally becomes an adult. 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 decision making.

At age 17 we will begin collaborating with youth and families to prepare the youth to transfer to an adult provider. We recommend this transfer occurs at age 18 or at least before the youth is discharged at age 21. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, portable medical summary and communicating with the adult provider about the unique needs of our patients.

If you have any questions or concerns, please feel free to contact your local CCSHCN Care Coordinator.

This transition statement was developed using information from the www.gottransition.org website.
Dear [Guardian Name(s)]:

As [child’s first name] nears [his] [her] 18th birthday (happy birthday!), we want to mention that as a legal adult, [he] [she] will be responsible for [his] [her] health care and CCSHCN enrollment. We will only be permitted to speak directly with [child first name] about [his] [her] care, due to privacy laws – unless [he] [she] provides us permission. Enclosed is a form for [child first name] to complete in the event that [he] [she] will need your involvement after age 18. This form should be returned to [child first name]’s care coordinator, [name of care coordinator] at the [regional office] CCSHCN regional office, at [address].

Another important form, the Consent for Treatment form, is also attached; this permits us to continue to provide services to [child first name] and we ask that [child first name] also sign and return this form after [his] [her] birthday.

We’d also like to remind you that CCSHCN care coordinators, social workers, and family consultants are able to assist you and [Child first name] in planning for transition needs, such as:

- Performing important health care skills – like understanding [his] [her] medical condition and being able to talk with doctors and other health care providers;
- Considering [his] [her] future goals – such as obtaining job-training skills or college; and
- Learning how to become independent – by preparing to become an adult and knowing [his] [her] rights and responsibilities.

Our staff will be discussing topics such as these with you and [Child First Name] during clinic appointments, and we encourage you to help prepare [him] [her] for these conversations and think about [his] [her] interests and goals. We are able to assist with referring [child first name] to programs in the community which may be able to help, as well.

We try to post helpful resources about successful transitions to adulthood on our website [http://chfs.ky.gov/ccshcn](http://chfs.ky.gov/ccshcn) and our agency Facebook page (link available on our website).

If you have any questions about this letter, please do not hesitate to contact me at (800) 232-1160, ext. 2002, or [child first name]’s care coordinator, [Name of Care Coordinator] at [Phone Number]. We look forward to helping you plan for [child first name]’s future!

Sincerely,

Lee Gordon
Transitions Administrator
[Date]

[Name of 18 year old]
[Address]
[City, State, Zip]

Dear [Name]:

As your 18th birthday approaches (happy birthday!), we want to mention that as a legal adult, you will be responsible for your health care and CCSHCN enrollment. We will only be permitted to speak directly with you about your care, due to privacy laws – unless you provide us permission. Enclosed is a release form to complete in the event that you will want the involvement of your parent or another adult after age 18. It is very important to sign and return this form on or after your 18th birthday. Another important form, the Consent for Treatment form, is also attached; this permits us to continue to provide services to you and we ask that you also sign and return this form after your birthday. Finally, a Notice of Privacy Practices is included, which informs you about how CCSHCN uses and protects your information. These forms should be returned to your care coordinator, [name of care coordinator] at the [regional office] CCSHCN regional office, [address].

We’d also like to remind you that CCSHCN staff are able to assist you in planning for future, and help you in areas like:

- Performing important health care skills – like understanding your medical condition and being able to talk with doctors and other health care providers;
- Considering your goals – such as obtaining job-training skills or college; and
- Becoming more independent – by preparing to become an adult and knowing [his] [her] rights and responsibilities.

Our staff will be discussing topics such as these with you during clinic appointments, and we encourage you to prepare by thinking about any assistance you may need with transitioning to adulthood.

We try to post helpful resources about transitioning to adulthood on our website (http://chfs.ky.gov/ccshcn) and our agency Facebook page (link available on our website).

If you have any questions about this letter, please do not hesitate to contact me at (800) 232-1160, ext. 2002, or your care coordinator, [Name of Care Coordinator] at [Phone Number]. We look forward to helping you plan for your future!

Sincerely,

Lee Gordon
Transitions Administrator
Dear parent/guardian:

As a part of our mission to enhance the quality of life for Kentucky's children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please fill out the following questions. Bring back to clinic and return with registration.

Clinic date: _______________ Patient Name: __________________________ Age: _____

If 3 or older, does your child have an IEP: Yes/No

If yes, would you like a Commission staff member to attend IEP meetings? Yes/No

If so, it is the family's responsibility to invite staff to each meeting in a timely fashion.

<table>
<thead>
<tr>
<th>0-4</th>
<th>Yes</th>
<th>No</th>
<th>Would Like More Info</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like to know about:</td>
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<tr>
<td>I am aware of government assistance programs (financial or food) that may be available and know how to access these services.</td>
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<tr>
<td>My child is reaching developmental milestones or is developing like other children.</td>
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<tr>
<td>I know about First Steps and Head Start and how to get my child into these programs.</td>
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<tr>
<td>My child needs additional therapies, therapists, services or resources.</td>
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</tbody>
</table>

If your child has an IEP or special needs concerns, answer the following:

- I know how to apply for SSI for my child.
- My child is 3 years old or older with a disability and still in diapers and I know how to get assistance paying for diapers.
- I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?

Is there something you are trying to overcome that we can help with? Yes/No? If yes, please explain.

________________________________________________________________________________________________________________________

Any questions or comments? __________________________________________________________________________________________

_______________________________________________________________________________________________________________________

CUP ID # __________________________
Dear parent/guardian:

As a part of our mission to enhance the quality of life for Kentucky’s children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please fill out the following questions. Bring back to clinic and return with registration.

Clinic date: _______________ Patient Name: _________________________________  Age:_____

School____________________________________ Grade:______ Grades________

IEP: Yes/No  If your child has an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No If so, it is the family’s responsibility to invite staff to each meeting in a timely fashion.

<table>
<thead>
<tr>
<th>Age 5-11</th>
<th>Yes</th>
<th>No</th>
<th>Would Like More Info</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>General information:</td>
<td></td>
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<tr>
<td>My child/family has computer access.</td>
<td></td>
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<tr>
<td>I understand my child should use a booster seat until age 8-12 or about 4'9”.</td>
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<tr>
<td>My child knows his/her address and phone number.</td>
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<tr>
<td>My child does home chores.</td>
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<tr>
<td>I keep a medical record of information on my child.</td>
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<tr>
<td>I am aware of the benefits of activities and camps for my child...including activities and camps for children with special needs like The Center for Courageous Kids, Special Olympics, KSD Summer School, etc.</td>
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<tr>
<td>I need behavioral support for my child.</td>
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</tbody>
</table>

If your child has an IEP or special needs concerns, answer the following:

| | | | |
|-----------------|--------|-----------------|
| I know about Special Needs Trust. | | |
| I need help with a specialized car seat for my child. | | |
| I am aware of adaptive equipment available for my child. | | |
| I am aware of Human Development Institute’s Comprehensive Disability Resource Manual. | | |
| I need help obtaining diapers/briefs for my child with a disability. | | |
| I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. | | |
| If you have one, which waiver do you receive? | | |

Is there something you are trying to overcome that we can help with? Yes/No  If yes, please explain.__________________________________________________________

Any questions or Comments?__________________________________________________________________________

______________________________________________________________________________________________

______________________________________________________________________________________________

CUP ID # __________________________
Dear parent/guardian:

As a part of our mission to enhance the quality of life for Kentucky’s children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please have your child answer the following questions and help them as needed. Bring back to clinic and return with registration.

Clinic date: _______________ Patient Name: ________________________________ Age: _____
School________________________________ Grade:______ Grades____________

**IEP:** Yes/No  If your child has an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No
If so, it is the family’s responsibility to invite staff to each meeting in a timely fashion.

---

### 12-14

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Beginning</th>
<th>Caregiver</th>
<th>No</th>
<th>N/A</th>
<th>I’d like help</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health</strong></td>
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<tr>
<td>I understand my diagnosis and can explain it.</td>
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<tr>
<td>I know the “danger signs” of my condition and when to seek medical help.</td>
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<tr>
<td>I tell the doctor how I am doing and answer questions.</td>
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<tr>
<td>I take my medicine with or without supervision.</td>
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<tr>
<td>I know the name of my medication(s) and the possible side effects.</td>
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<tr>
<td>Without parental prompting, I have good hygiene and am well groomed: clean hair, bathe regularly, brush/floss daily, wears clean clothes.</td>
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<tr>
<td>I have questions regarding sexuality.</td>
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</tbody>
</table>

**For Girls Only** - I have questions regarding my menstrual period.

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**If your child has an IEP or special needs concerns, answer the following:**

- I know how to take care of my medical equipment, i.e. hearing aids, wheelchair, leg braces, walker, breathing equipment, etc.

(over)
<table>
<thead>
<tr>
<th>12-14</th>
<th>Yes</th>
<th>Beginning</th>
<th>Caregiver Doing</th>
<th>No</th>
<th>N/A</th>
<th>I'd like help</th>
</tr>
</thead>
</table>

**Independent living**

- I care for my own personal needs, i.e., feeding, bathing, dressing, grooming, or know how to attain help with them.
- I have an Emergency Plan of some type (health or natural disaster) and know how to call 911.
- I know how to study and am responsible for my homework.
- I spend time with friends for social activities.
- I do more advanced chores at home.
- I can name 3 things I am good at and have fun doing.
- I understand the value of an education and how that will help me achieve my work goals.

**If your child has an IEP or special needs concerns, answer the following:**

- I can acquire a service animal, if needed.
- I understand the Americans with Disabilities Act/Individual with Disabilities Education Act.
- At age 14, I attend my IEP/504 meetings.
- I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?

Please answer the following questions. Because things change, some questions may be asked every year.

I plan to be a ____________________________ when I grow up to support myself financially.

I understand I will have to ____________________________ to achieve this goal.

Is there something you are trying to overcome that we can help with? Yes/No If yes, please explain. ____________________________

For parents, are you able to support your child’s goals? Yes/No Please explain. ____________________________

For parents, what do you see your child doing after graduation? ____________________________

Any questions or comments? ____________________________

CUP ID # ____________________________
Dear parent/guardian:

As part of our mission to enhance the quality of life for Kentucky’s children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please have your teen answer the following questions and help them as needed. Bring back to clinic and return with registration.

Clinic date: _______________ Patient Name: ______________________________ Age: ____
School ______________________ Grade:______ Grades__________

IEP: Yes/No If your child has an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No If so, it is the family’s responsibility to invite staff to each meeting in a timely fashion.

<table>
<thead>
<tr>
<th>15-17</th>
<th>Yes</th>
<th>Beginning</th>
<th>Caregiver Doing</th>
<th>No</th>
<th>N/A</th>
<th>I’d like help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
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<tr>
<td>I communicate problems/concerns to my doctor.</td>
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<tr>
<td>I take my medication/do treatments as scheduled, if applicable.</td>
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<tr>
<td>I’m an informed participant taking part in making medical decision for myself.</td>
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<tr>
<td>I inform family of my need for medicine ordered and refills.</td>
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<tr>
<td>I talk with my doctor/nurse/social worker about the need to choose an adult health care provider when I turn 18.</td>
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<td>I am familiar with health insurance and how it works - i.e. insurance plans, deductibles, co-pays, etc.</td>
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<tr>
<td>I understand the importance of organizing and keeping my medical records and receipts.</td>
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<tr>
<td>I know the importance of having health insurance coverage and what will happen to it at age 18.</td>
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</table>

Any questions or comments? ________________________________

________________________________________________________

(Over)

CUP ID # __________________________
### Independent living

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Beginning</th>
<th>Caregiver Doing</th>
<th>No</th>
<th>N/A</th>
<th>I'd like help</th>
</tr>
</thead>
<tbody>
<tr>
<td>I help to plan and prepare meals/food.</td>
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<tr>
<td>I can budget money and save up for something.</td>
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<tr>
<td>I am deciding what my future plans i.e. work, secondary education, vocational training, Job Corp, military, etc.</td>
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<td>I am learning about healthy behaviors such as exercise and nutrition that help me stay well.</td>
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<td>I have a part time job or volunteer.</td>
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<td>I am preparing for my future transportation needs by learning to drive, managing public/private transportation, understanding ADA transportation, or planning to be evaluated for the ability to drive, if applicable.</td>
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<tr>
<td>I intend to register to vote at age 18. I understand the importance of exercising my right to vote. And if disabled, I understand the value of voting for candidate’s who support disability rights and services.</td>
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</tbody>
</table>

**If your child has an IEP or special needs concerns, answer the following:**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Beginning</th>
<th>Caregiver Doing</th>
<th>No</th>
<th>N/A</th>
<th>I'd like help</th>
</tr>
</thead>
<tbody>
<tr>
<td>I attend my IEP/504 meetings.</td>
<td></td>
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<tr>
<td>I am planning for my future by being ready to list vocational goals on my IEP at age 16.</td>
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<tr>
<td>I know to reapply for SSI at age 18 because only my income will be considered at that time.</td>
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<tr>
<td>Issues of giving medical consent, guardianship, or POA at age 18 are being considered.</td>
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<tr>
<td>I understand how I can work and still draw disability. I know about Social Security Administration (SSI or SSDI) work incentives-PASS plan, 1619A&amp;B, Ticket to Work.</td>
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<tr>
<td>I am aware of services for the disabled including Voc Rehab, School to Work, Supported Employment, Carl Perkins, Adult Day Treatment, Adult Day Care, etc.</td>
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<tr>
<td>I understand my rights under the American Disabilities Act.</td>
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<tr>
<td>With a developmental disability, I understand, I can stay in High School until age 21.</td>
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<tr>
<td>I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services.</td>
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<tr>
<td>If you have one, which waiver do you receive?</td>
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</tr>
</tbody>
</table>

Please answer the following questions. Because things change, some questions may be asked every year.

I plan to be ________________________ when I grow up to support myself financially.

I understand I will have to ________________________ to achieve this goal.

Is there something you are trying to overcome that we can help with? Yes/No If yes, please explain. ________________________

For parents, are you able to support your child’s goals? Yes/No Please explain. ________________________

For parents, what do you see your child doing after graduation? ________________________

Any Questions or Comments? ________________________

CUP ID # __________________________
Dear patient (or guardian, if applicable):

As a part of our mission to enhance the quality of life for Kentucky’s children with special health care needs, we would like to assist you in finding resources and help with developmental tasks. Please fill out the following questions. Bring back to clinic and return with registration.

Clinic date: _______________ Patient Name: __________________________ Age: ____
School __________________________ Grade:______ Grades ______________

IEP: Yes/No 
If you have an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No
It is the family’s responsibility to invite staff to each meeting in a timely fashion.

<table>
<thead>
<tr>
<th>HEALTH</th>
<th>Yes</th>
<th>Beginning</th>
<th>Caregiver</th>
<th>No</th>
<th>N/A</th>
<th>I’d like help</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have plans for adult health care providers (Primary care, Specialty, Dental, DME, Pharmacy, Therapy and Mental Health) and have made initial appointments to establish care with them or are already seeing them.</td>
<td></td>
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<tr>
<td>I make a list of questions to ask my doctors so I can remember to ask them.</td>
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<tr>
<td>I make my own medical decisions or have other arrangements in place.</td>
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<tr>
<td>I can explain to others how our family’s customs and beliefs might affect health care decisions and medical treatments.</td>
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<tr>
<td>I follow up on any referrals for tests, check-ups, or labs.</td>
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<tr>
<td>I call the doctor about any unusual changes in my health i.e. allergic reactions.</td>
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<tr>
<td>I have chosen a pharmacy where my current and new prescriptions can be filled. I am aware of generic medications saving me money.</td>
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<tr>
<td>I am aware of Prescription Assistance programs if I do not have insurance or do not have adequate insurance.</td>
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<tr>
<td>I have a medical history summary that I carry which includes the list of medication I take and the dosage that can be given to new doctors.</td>
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<tr>
<td>I manage my medical appointments and make arrangements for transportation to attend if needed.</td>
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<tr>
<td>If I am no longer eligible for Medicaid, I have looked into options and applied for other funding resources.</td>
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<tr>
<td>I know what to do for minor ailments like a cold and health emergencies like pressure wounds.</td>
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<td></td>
</tr>
<tr>
<td>I sign my own release of information forms or have a plan in place for guardianship, POA, conservator, etc.</td>
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<td>I am aware of support groups (for example, seizure or autism, etc.) in my area to supplement family support.</td>
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(over)
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<tr>
<th>18-21</th>
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<tbody>
<tr>
<td><strong>Independent living</strong></td>
<td>Yes</td>
<td>Beginning</td>
<td>Caregiver Doing</td>
<td>No</td>
<td>N/A</td>
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<td>I have plans for after high school.</td>
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<td>I know what to do to enroll in school or training and apply for financial aid.</td>
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<tr>
<td>I have plans for independent living, housing, transportation.</td>
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<td>I know how to manage money and budget household expenses.</td>
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<td>I have a driver’s license or state ID.</td>
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<td>I work or volunteer.</td>
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<td>I know about transferring records when I turn 21 years old.</td>
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<td>I have shopping, cooking, laundry, and housekeeping skills.</td>
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<tr>
<td>I have registered to vote and understand the importance of exercising my right to vote. And if disabled, I understand the value of voting for candidates who support disability rights and services.</td>
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<td>I can take care of my personal needs, have identified someone to help, if needed, or I know how to hire a personal attendant, if needed.</td>
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**If your child has an IEP or special needs concerns, answer the following:**

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<tr>
<td>I know how to get any accommodations I need for work or school. I am aware of the Job Accommodation Network which is a free service.</td>
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<tr>
<td>I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?</td>
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</table>

Please answer the following questions. Because things change, some questions may be asked every year.

I plan to be a _________________________________ to support myself financially. I understand I will have to ____________________________________________________________ to achieved this goal.

Is there something you are trying to overcome that we can help with? Yes/No If yes, please explain.

_______________________________________________________________________________________________________________________

_______________________________________________________________________________________________________________________

For parent/guardian, are you able to support your young adult’s goals? Yes/No Please explain. __________________________

________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________

For parent/guardian, what do you see your young adult doing after graduation? ______________________________

________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________

Any questions or comments? __________________________

________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________
Adult Provider Outreach Folder Contents

Organization-Specific Resources:
- Welcome to The Coordinating Center and Transition Connection Initiative (TCI) Contact information
- Rare and Expensive Case Management (REM) Trifold
- Adult Community Services (ACS) Information Sheet
- TCI Introductory Letter for Adult Health Care Providers
- TCI’s Mission Statement and Approach to Health Care Transition (HCT Policy)
- Delineation of Roles table (HCT task responsibility – Clinical Care Coordinator, Pediatric Primary Care Provider (PCP), Adult PCP, Youth/family)
- Medical Summary and Emergency Care Plan
- Youth Transition Readiness Assessment
- Parent/Caregiver Transition Readiness Assessments

State and Local Resources:
- Maryland DHMH Youth to Young Adult HCT Home Page
  https://phpa.health.maryland.gov/genetics/Pages/Health_Care_Transition.aspx
- MD Office of Genetics and People with Special Health Care Needs (OGPSHCN) Special Needs Resource Locator Home Page
  specialneeds.dhmh.maryland.gov
- MD Transitioning Youth Home Page
  http://mdod.maryland.gov/education/Pages/transitioningyouth.aspx
- MD Developmental Disabilities Administration Home Page
  https://dda.health.maryland.gov/Pages/home.aspx

Got Transition Practice Resources:
- Got Transition Resources overview
  http://www.gottransition.org/providers/index.cfm
- Six Core Elements of HCT 2.0 Side-by-Side Version
  http://www.gottransition.org/resourceGet.cfm?id=206
- Guardianship and Alternatives for Decision-Making Support
  - Handout
    http://www.gottransition.org/resourceGet.cfm?id=17
  - Webinar
    https://www.youtube.com/watch?v=0xXELCIMHHE&feature=youtu.be
- Integrating Young Adults with Intellectual and Developmental Disabilities into Your Practice: Tips for Adult Health Care Providers
  http://www.gottransition.org/resourceGet.cfm?id=367
- Communicating Effectively with Adults with Developmental Disabilities
  https://vkc.mc.vanderbilt.edu/etoolkit/general-issues/communicating-effectively/
- Incorporating Pediatric-To-Adult Transition into NCQA Patient-Centered Medical Home Recognition
  http://www.gottransition.org/resourceGet.cfm?id=444
- American College of Physician’s (ACP) Pediatric to Adult Care Transitions Initiative
  https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative
- 2017 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care
  http://www.gottransition.org/resourceGet.cfm?id=352
Adult Provider Transfer Packet Contents

- Most recent transition readiness assessments
- Medical summary and emergency care plan
- Care management plan
- Plan of care for the next year
- Condition-specific fact sheet, if available
- Legal decision-making supports documentation, if needed
- Adult disability resource list
- Link to pediatric provider for information/consultation

TCI Criteria for Successful Completion of Youth to Adult Transition

- Successful transfer to Adult Primary Care Provider (PCP)
- Successful transfer to all necessary Adult Specialty Care Providers (SCP)
- Has adult health insurance
- Legal decisions about health care decision-making resolved and documented, if needed
- All adult disability supports in place

The mission of The Coordinating Center is to partner with people of all ages and abilities and those who support them in the community to achieve their aspirations for independence, health and meaningful community life.
Delineation of Roles for The Coordinating Center’s Health Care Transition Approach

<table>
<thead>
<tr>
<th>Nine Core Elements of HCT</th>
<th>Clinical Care Coordinator (CCC) Role</th>
<th>Pediatric Primary Care Provider (PCP) Role</th>
<th>Adult Primary Care Provider (PCP) Role</th>
<th>Youth and Family/Caregiver Role</th>
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<tr>
<td>TCC HCT Mission Statement and Approach - #1</td>
<td>Communicate TCC HCT mission statement and approach to youth, parent/caregiver and PCP. Letters and script provided.</td>
<td>Review TCC HCT policy to be sure there is no discordance with practice approach.</td>
<td>Review TCC HCT policy to be sure there is no discordance with practice approach.</td>
<td>Be aware of TCC HCT policy and ask questions if necessary.</td>
</tr>
<tr>
<td>Tracking and Monitoring - #2</td>
<td>Document HCT in YAT tab and CMP goal progress notes in CARMA</td>
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<tr>
<td>Transition Readiness Assessment (TRA) - #3</td>
<td>Administer at age 14 – 16 and yearly through time of transfer. Identify issues, incorporate as transition goals into Care Management Plan. Share goals with pediatric PCP and with youth/family. Work with youth and family on health care self-management skills training as identified in the TRA.</td>
<td>Work with CCC, youth and family to improve youth’s transition readiness skills.</td>
<td>Work with CCC, youth and family to improve young adult’s self-care skills.</td>
<td>Take the TRA. Identify issues and set HCT goals with CCC and PCP. Work on acquisition of health care self-management skills with family, CCC and pediatric PCP. Retake the TRA yearly to identify continuing issues, document progress and set new goals. Work with adult PCP on integration into adult model of medical care.</td>
</tr>
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<tr>
<td><strong>Care Management Plan - #4</strong></td>
<td>Incorporate HCT self-care skill issues identified on TRA into CM Plan goals and share with youth, family and PCP. Update as needed.</td>
<td>Review Care Management Plan regularly and share with youth and family. Update as needed.</td>
<td>Review Care Management Plan regularly and share with young adult and family. Update as needed.</td>
<td>Review Care Management Plan regularly, acquire HCT self-care skills and update as needed.</td>
</tr>
<tr>
<td><strong>Medical Summary and Emergency Care Plan (ECP) - #5</strong></td>
<td>Check that all areas are addressed and information is current in CARMA. Print out report and share with youth, family and PCP.</td>
<td>Review Medical Summary and ECP, update regularly. Share with youth and family.</td>
<td>Review Medical Summary and ECP, update regularly. Share with young adult and family.</td>
<td>Review Medical Summary and ECP, provide more detail if necessary. Update regularly. Have available always. Share with health care providers.</td>
</tr>
<tr>
<td><strong>Decision-Making Capacity - #6</strong></td>
<td>Address this issue with youth, family and PCP and refer to legal resources if necessary. Finalize decision-making supports by age 18 and communicate outcome to PCP.</td>
<td>Legal documentation provided, if needed.</td>
<td>Legal documentation provided, if needed.</td>
<td>Discuss this issue with each other and reach agreement. Finalize decision-making supports by age 18. Obtain legal documentation if necessary. Revisit issue as needed.</td>
</tr>
<tr>
<td><strong>Identify Adult PCP - #7</strong></td>
<td>Assist youth and family in identification of adult PCP. Confirm availability of adult PCP. Work with pediatric PCP to complete transfer package. Later, assist in identification of adult specialty care providers and adult disability services.</td>
<td>Work with CCC to complete transfer package to adult PCP. Send adult PCP the complete transfer package. Offer the adult PCP consultation assistance, as needed.</td>
<td>Share practice information (FAQs) with youth, family and CCC. Integrate youth into adult medical model. Assist in identification of adult specialty care providers and adult disability services.</td>
<td>Think about what services you need from an adult PCP (location, hours, insurance, hospital referrals, etc.) Work with CCC to identify adult PCP. Ask pediatric PCP and specialists for recommendations. Later, work with CCC and PCP to identify adult subspecialists and adult disability services.</td>
</tr>
<tr>
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<tr>
<td>First Adult PCP Appointment - #8</td>
<td>Ensure that youth/family makes and attends first appointment and intends to stay with the new PCP. Document date of transfer.</td>
<td>Document date of transfer.</td>
<td>Receive transfer information from pediatric PCP. Acknowledge transfer package received. Discuss HCT, confidentiality and practice FAQs at first visit.</td>
<td>Schedule and keep first visit with adult PCP. Share updated Med Summary/ECP. Make sure that transfer package has been received. Discuss concerns and health goals.</td>
</tr>
<tr>
<td>HCT Feedback Survey - #9</td>
<td>Encourage youth and families to complete the TCI survey. Review client feedback results and incorporate into ongoing HCT efforts.</td>
<td></td>
<td>Complete the TCI survey. Offer feedback, which will be incorporated into ongoing HCT efforts, and advocate for improvement.</td>
<td></td>
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</table>

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