Webinar # 4  May 31, 2018
Integration Into Adult Care

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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 #4: Integration into Adult Care

Objectives

At the conclusion of Webinar 4, attendees will be able to...

- Support the development of HCT Policy/Welcome and FAQs information by the adult practice(s) who will accept young adults and share this info with pediatric practice(s) to share with their YA

- Facilitate the initial appointment to the adult clinician including confirmation of receipt of the transfer package and covering the youth during the bridge time to the adult appointment

- Discuss the Indiana Title V example of supporting adult clinicians, YA who are transferring, and linking to adult disability resources
Webinar #4
Handouts

- Webinar #4 Slideshow
- Got Transition’s Welcome and FAQ information and practice resource, “Integrating Young Adults with ID/DD into your practice: Tips for the Adult Health Care Provider”
- Indiana’s CYACC’s resources: Activated Patient, Visit Summary Action Plan Template, Adult practice support: For the PCP: Caring for Adults (Adherence), Caring for Adults (Activated Patient)
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
Webinar #3
Review: Transfer to Adult Care

- 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
## Six Core Elements: Roles of Clinicians

<table>
<thead>
<tr>
<th>Practice/Provider</th>
<th>#1 Transition/Care Policy</th>
<th>#2 Tracking and Monitoring</th>
<th>#3 Transition Readiness/Orientation to Adult Practice</th>
<th>#4 Transition Planning/Integration into Adult Approach to Care/Practice</th>
<th>#5 Transfer of Care/Initial Visit</th>
<th>#6 Transition Completion/On-going Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pediatric</strong></td>
<td>Create with youth/family</td>
<td>Track youth and family preparation and transfer</td>
<td>Discuss transition readiness assessments (RA)</td>
<td>Develop transition plan, with RA skills, prepare youth for adult approach to care/ Communicate with new clinician</td>
<td>Transfer of care with medical info, communicate, assist with YA coming to first AP visit</td>
<td>Obtain feedback of transition experience and confirm YA seen by the new clinician</td>
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<tr>
<td><strong>Adult</strong></td>
<td>Create with young adult</td>
<td>Track YA's integration into adult care</td>
<td>Discuss Welcome and FAQs with pediatric practices, YA and guardian, if needed, on first visit</td>
<td>Communicate with referring ped clinician (PC), request receipt of transfer package</td>
<td>Collab with PC to ensure YA 1st visit, review transfer package, address YA's needs &amp; concerns at initial visit, update self-care assessment &amp; medical summary</td>
<td>Confirm transfer completion with PC, provide ongoing care with self-care skill building, link to needed specialists</td>
</tr>
</tbody>
</table>

* Providers that care for youth/young adults throughout the life span could utilize both sets of core elements without the transfer process components
Transfer Process to Integrate into Adult Health Care

- Preparing the Transfer
- Communication
- Integration into Adult Care/Transfer Completed

Pediatric visit

Bridge

Adult visit
Preparing the YA for Transfer

- YA and pediatrician/CC identify new adult provider (with adult clinician welcome letters/policies available)
- Discuss role of the primary care clinician in adult health care system
- Give YA info to call adult clinician’s office/joint call
- Transfer packet that also includes special non medical information to assist adult provider to engage YA at first visit/heads up on what needs should be focused on during first visit/consider including a condition fact sheet
- Peds/CC assure YA and Adult Clinician that Peds will cover their care until 1st adult clinician visit
Bridge: Communication

- Peds MD sends message (in EMR if possible)/letter to internal medicine (IM) physician and/or nurse
- Peds sends reminder to the YA to contact new provider office
- Peds/CC assure YA and Adult Clinician that Peds will cover their care until 1st adult clinician visit
- Adult office nurse calls YA to schedule first appointment and identify needs for accommodations
- Pediatric or CC follow up to learn if the young adult went to first appt and have a plan to follow up if the YA did not come to the 1st appt
- Follow up with YA to obtain feedback on the process after first Adult Clinician appt
Adult Practice
HCT Policy/Welcome Letter Content

• Welcoming Language
• Written for and reviewed by YA
• Explanation of patient (YA) and adult model of care
• Privacy and consent information; if needed legal information about decision making support
• Medical information needed to be sent to the adult clinician’s office before 1st appointment
• Example at http://www.gottransition.org/resourceGet.cfm?id=212
At our practice, you have the right to:
• Be treated in a caring way
• Make your own decisions
• Talk to your health care provider alone
• Have things explained in a way that you understand
• Have access to your medical information

In turn, you are responsible for:
• Keeping appointments and cancelling appointments in advance
• Telling us about your current symptoms and health history to help us treat you
• Following treatment plans that you develop with your health provider
• Asking questions about your care
• Knowing what your insurance covers
Below is a list of frequently asked questions about our practice. If you have a question that is not listed below, feel free to ask any of our staff. We look forward to having you in our practice.

Q: What services does the practice provide (including preventive, acute and chronic illness care, and, if offered, sexual health, mental/behavioral health, wellness programs, and other specialty care)?

Q: Are services confidential?

Q: Where is the office located (including map and nearest public transportation)?

Q: What providers are available to care for young adults?

Q: What are the office hours (including walk-in options, if available)?

Q: Are there after-hours call-in options?

Q: How do I schedule, reschedule, or cancel an appt?

Q: What insurance is accepted?

Q: How much do visits cost?

Q: What should I bring for my first appointment?

Q: What resources are available to assist me to learn about wellness and self-care (e.g., nutrition and fitness classes, support groups, special apps or websites, local community resources).
Introductory Remarks

Shirley Payne, MPH

Director, Children’s Special Health Care Services

Indiana State Department of Health
Introduction into Adult Care

Mary R Ciccarelli, MD

Indiana University School of Medicine

May 2018
Center for Youth and Adults with Conditions of Childhood

Indiana Title V program - Statewide Transition Service

Team – Social workers, nurses, med-peds physicians, parent/youth representatives

- Improve youth to adult healthcare transition across the state
  - Consultation & transition care coordination for youth ages 11-22 with any chronic diagnosis who have issues meeting their transition needs
  - Education – IUSM campus learners, Indiana primary & specialty care, national consults

- Funding: Indiana State Dept of Health MCH, IUSM Dept of Pediatrics, Eskenazi Health
CYACC goals

- To improve statewide transition anticipatory guidance for Indiana youth ages 11-22
- To increase the confidence of primary care providers in providing transition services
- To increase the skills of health care professional trainees in transition care
Transition planning action items

- Health care financing
- Primary care
- Subspecialty team
- Care coordination
- Health care needs
- Health habits/risks
- Puberty/sexuality
- Mental health
- Self management
- Decision making supports
- Caregiver needs

- School/work
- Independence living
- Community participation
- Legal issues/finances
Four categories of services

- Chronic illness
  - Managing treatment plan
  - Working healthcare team
  - Adherence supports
- Physical disability
  - Physical living accommodations
  - Training new caregivers
  - Universal design environment
- Intellectual disability
  - Balancing supervision vs. autonomy
  - Sensing and communicating bodily needs
  - Community inclusion
- Serious mental illness
  - Planning for fluctuating course
  - Denial/stigmatization
  - Springing power of attorney
Developmental Expectations

Developmental ages & stages

• 11-13 – Developing self-image as “abled” vs. “disabled”
• 14-16 – Increasing independence of high school environment, evolving metacognition, “why me” disease non-acceptance
• 17-19 – Exiting high school, assuming decision-making role, beginning transfers, issues with adherence/self-regulation
• 20-22 – Moving to adult care team, exiting special education/college, continued work on disease acceptance and self-regulation
• 23-25 – Working through disease acceptance, emerging into self-regulating of adulthood
Care Teams - based on Scope of Practice

**Pediatric Medicine**
“Best interest of the child” by the proxy caregiver
9% visits for routine chronic care
- Asthma 9% ages 0-18
- ADHD 5.4%
- Obesity
- Allergies
- Development behavior issues

Rezaee ME. Prev Chron Dis, 2015

**Adult Medicine**
“Autonomy” as an adult in decision making
33% visits for routine chronic care
- Hypertension 32.5% ages 45-64
- Hyperlipidemia 21.5%
- Arthritis 17.3%
- Diabetes 13.9%
- Depression 12.2%
- Asthma 5.7%

NAMCS, 2012
Scaffolding supports
“Railings on the transition bridge”
Anticipatory Adherence Counseling

ACTION PLAN

Name: ________________________________ Date: ________________________________

Doing Well:
Here are the ways you can tell you are doing well:

• ________________________________
• ________________________________
• ________________________________

These are things you need to do every day to stay well. Follow this plan every day:

• ________________________________
• ________________________________
• ________________________________

Getting Worse:
These are signs of new problems:

• ________________________________
• ________________________________
• ________________________________

You need to notice when your health is getting worse with the usual plan. Add these to your daily routine:

• ________________________________
• ________________________________
• ________________________________

Medical Alert!
These are urgent problems to solve right now:

• ________________________________
• ________________________________

If your attempts to help the problem don’t work, you need to act now and get help. Do this immediately:

• ________________________________
• ________________________________

Call the Doctor’s office NOW. Tell them you have an urgent problem and you need help today!

Doctor: ________________________________
Phone: ________________________________

Reasons to get emergency medical help:
• ________________________________
• ________________________________

Go to the hospital or call an ambulance (Call 911):

Who else do you need to tell? ________________________________
Health habit smartphone apps
Self-management smart phone apps

Medisafe

MedCoach
Smartphone – In Case of Emergency

- **iPhone’s Settings**
  - SOS
  - Emergency Contacts in Health
  - Create Medical ID

- **Android**
  - QuickICE app

- [http://incaseofemergency.org](http://incaseofemergency.org)
Structuring supports - to track & monitor high risk patients

- **Transition Readiness Assessment Questionnaire** was completed by the youth, for a score of **XX**.

- We believe the youth *currently*
  - needs significant prep to be able to navigate the adult health care system
  - is getting ready to navigate the adult health care system
  - is ready to navigate the adult health care system

  - Wood, Sawicki, Reiss, Livingood, Kraemer, 2014,
    [http://hscj.ufl.edu/jaxhats/traq/](http://hscj.ufl.edu/jaxhats/traq/)
Care coordination needs assessment

Social vs. Medical Complexity

- Low stressors - serve as own Advocate
- Moderate stressors – are well Engaged in planning
- High stressors – are In need of additional supports

“Based on a life stressor assessment we recommend that this youth...
- (strongly needs ongoing care coordination), High =
- (likely needs ongoing care coordination), Moderate =
- (is excellent at self-advocacy and needs limited ongoing care coordination supports). Low BLSS”

Robert Nickel, Bob’s Level of Social Support – OSHU, 2011
## Medically complex patient shared plan of care

### SHARED CLINICAL PLAN OF CARE

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Receiving office supports

- Policy & Office FAQs
- Receipt of transfer packet
- Office tools
- Care Team education handouts
- Health system and community resources
Transfer Packet Receipt

- Confirmation methods
  - Verify appointment kept
  - Phone/fax/email confirmation of receipt of packet
  - Secure messaging system within EHR or cross-systems
  - Use of patient portal
Activated Patient: Visit Preparation and Summary

Use the first half of this form to prepare for an office visit.
Use the second half of this form to review the plans made at the visit.

Patient’s Name ___________________________ Date/Time of Visit

Caregiver Name, If applicable ___________________________

Patient Goals for visit:

Reasons for Visit: ____________________________________________

☐ Health concerns since last visit: ____________________________________________

☐ Other providers seen or tests performed since last visit: __________________________

☐ Test results to discuss: ____________________________________________

☐ Medication refill needs: ____________________________________________

What is a medical home? Why do you need a primary care doctor?

A medical home is your “primary care” doctor’s office that you should visit for most of your health care needs. The Cystic Fibrosis Foundation’s patient education programs want to help you get ready to work well with your primary care doctor, and help you understand what a medical home is and why it is important to have one. You may find primary care as an adult seems different than when you were a kid, and we want you to be ready for these changes.

You will get better quality and safer health care if you work well with your primary care doctor in your medical home.

Your doctor’s office staff will know you and all of your medical history, and think about you as an individual. They will help plan for your future health. Your doctor’s office can help you learn to organize your own health care, and help you get the things you need through the health care system in the way that is best for you.

It is important to see your primary care doctor often enough so he or she knows what is going on with you. It is encouraged to visit your primary care doctor at least once a year.

Choosing to go to your Primary Care Doctor vs. the Emergency Room:

Going to your doctor is usually much cheaper than going to the emergency room. Your doctor knows about your health history, and things that are unique to you.

Emergency rooms are often much more expensive than your primary care doctor’s office. Your doctor focuses on problems you are having that moment, such as trauma, accidents, and illnesses where you end up being admitted to the hospital, but they don’t always help with other things like medication prescription or small health issues.

When you’re not feeling well, you should first talk to your primary care doctor or nurse to get help deciding what you should do next.

Working with Subspecialists:

Subspecialists are trained to help you with the special issues that you see them for, such as a cardiologist for your heart or a nephrologist for your kidneys. But subspecialists do not necessarily treat all of your health subspecialist care as an adult seems to be different than when you were younger. Your primary care doctor will help you figure out when to go to subspecialist.

How to answer these questions:

1. Do you have a primary care doctor?
2. What kind of changes do you get with your primary care doctor?
3. What kind of tests do you have done with your primary care doctor?
4. What kind of test do you have done with your primary care doctor?
5. What do you need to take care of at your next primary care doctor appointment?
Young adult healthcare issues

FOR THE PCP—Caring for Young Adults who Enter Your Adult Practice: Encouraging Young Adults to be Activated Patients

- Young adults are defined as ages 18 to 25. When young adults with chronic medical conditions transition to adult providers, they may need to adjust to a new adult model of care. They must learn self-management skills, rather than relying on their parents or caregivers.
- Among all patients, there are varying levels of self-management skill or “activation.” Activated patients have more positive outcomes and more appropriate health care utilization, which is often more efficient.
- Providers should assess self-management and patience socialization as part of assessment outcomes. Enhance patient self-management strategies (systematic reviews and interventions to increase patients’ skills and confidence in managing their health problems—May, 2013).

Using a Transition Readiness Tool

The TRAQ is a validated transition readiness tool. http://www.consumer.gov/youth

Sample questions:
- Do you do the doctor’s office to make an appointment?
- Do you follow up any referral he or she asks you to?
- Do you know your doctor’s name?
- Do you know your doctor’s appointment hours?
- Do you know how to contact your doctor after hours?
- Do you know what to do if you are not sure about a medication or symptom?
- Do you know if you are taking a medication the right way?
- Do you know what to do if you are not sure about a medication or symptom?

FOR THE PCP—Caring for Young Adults who Enter Your Adult Practice: Adherence Issues in Young Adults

- Young adults are defined as ages 18 to 25. When young adults with chronic medical conditions transition to adult providers, they may need to adjust to a new adult model of care. They must learn self-management skills, rather than relying on their parents or caregivers.
- Adherence is the patient’s active, intentional, and responsible process of taking prescribed medications or following the advice of a health care provider (May, 2013).
- Adherence is a problem among young adults, and there is a higher rate of discontinuing medication among young adults than older adults. This is demonstrated in a recent study that showed a higher rate of discontinuing medication among young adults.

KEY BARRIERS TO ADHERENCE IN YOUTH ADULTS: The Perfect Storm

1. Incomplete task memory may lead to poor adherence, impulsivity, and gaps in execution skills such as prioritization, problem solving, and risk identification.
2. Gaps are more common in knowledge regarding their conditions and treatments, as young adults may not have access to education and training in self-management.
3. Perceptions of independence may fuel a desire for personal freedom and perceived ability to make decisions without parental involvement.
4. During the transition, adolescents who feel less knowledgeable about their health and treatment may be more likely to discontinue medication or follow-up appointments.

METHODS TO MAXIMIZE ADHERENCE IN YOUTH ADULTS

- Use descriptive and non-judgmental discussion to promote trust in a new physician relationship.
- “Many patients find it hard to remember to take pills twice a day— is it hard for you?”
- Screen and address potential mental health problems—depression and anxiety, in particular.
- Provide repeated education through a variety of media—oral, written, and Internet resources.
- Use motivational interviewing techniques to work with patients’ ambivalence.
- Share the latest research on the topic, and if possible, measure the extent to which you perceive improvement in the nurse–patient relationship by using a standardized measure.
- Balance structure and flexibility in the shared plan of care.
- Sustainability: 1) you sign on to a new system, 2) you can make changes, and 3) maintain the link between care and medication.
- Simplify regimens, use smaller drug doses, when possible.
- “If you take your dose as you take your lab, and improve, you help the side effects you don’t like.”

- “What do you want to make it easier to follow your treatment plan?”
- Use safety net and monitoring—pharmacies, family, reminders, and follow-up contacts.
- Use motivational interviewing techniques to work on patients’ ambivalence.
- “How can we make it easier for you to follow your treatment plan?”
- Use safety net and monitoring—pharmacies, family, reminders, and follow-up contacts.
Community Supports

- Parent to Parent Networks –
  - About Special Kids, Family Voices, Insource
- Centers for Independent Living – CIL - Accessability, Inc - Indpls
- Self-Advocates - ARC of Indiana, Self Advocates IN
- Diagnosis-specific organizations
  - Down Syndrome Indiana
  - United Cerebral Palsy Indiana
  - Autism Society of Indiana
- Medical legal partners - Indiana Legal Services
  - UCEDD - Indiana Institute on Disability and Community
  - Disability awareness - Governor’s planning council
  - PAS - Indiana Disability Rights

Indiana - Family Social Service Administration
- Division Disabilities Rehabilitative Services
- Bureau of Developmental Disabilities
  - Community Integration Habilitation & Family Support waivers
  - Vocational Rehabilitation
  - Blind & Deaf services
- Aging services - Area agencies on aging and disability - AAA
  - Aged & Disabled waiver & Adult protective services

- Division Mental Health & Addiction
- Office of Medicaid Policy & Planning
- Division of Family Resources

Indiana State Department of Health
- Office of Primary Care
- Chronic Disease
Questions?

- Are you providing the YA with a list of adult clinicians (with Welcome information) that are available to care for them?
- What is your plan to work with the YA to be an engaged patient in the adult health care setting?
- How are you supporting the new adult clinician for the first visit?
- How does Indiana support their YA and adult PCPs through the transfer process?
Upcoming Title V Care Coordination Webinars

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

To register, please visit Got Transition’s website under News & Announcements (www.gottransition.org)
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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