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 4 · Integration into Adult Care

- Ensuring welcome and orientation FAQs from the adult practice to transferring young adults and pediatric practice
- Facilitating initial appointment to adult doctor, including confirmation of receipt of transfer package
- Supporting adult practice with CC assistance from Title V and linking to adult disability resources

Click here to view webinar recording on YouTube

MATERIALS INCLUDE:

- Care Coordination Webinar 4 Slides: Integration into Adult Care
- Indiana Transition Materials
- Sample Welcome and Orientation of New Young Adults
- Integrating Young Adults with Intellectual and Developmental Disabilities into Your Practice

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

Webinar # 4 May 31, 2018
Integration Into Adult Care

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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

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- 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

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Webinar #3 Review: Transfer to Adult Care

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- 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

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

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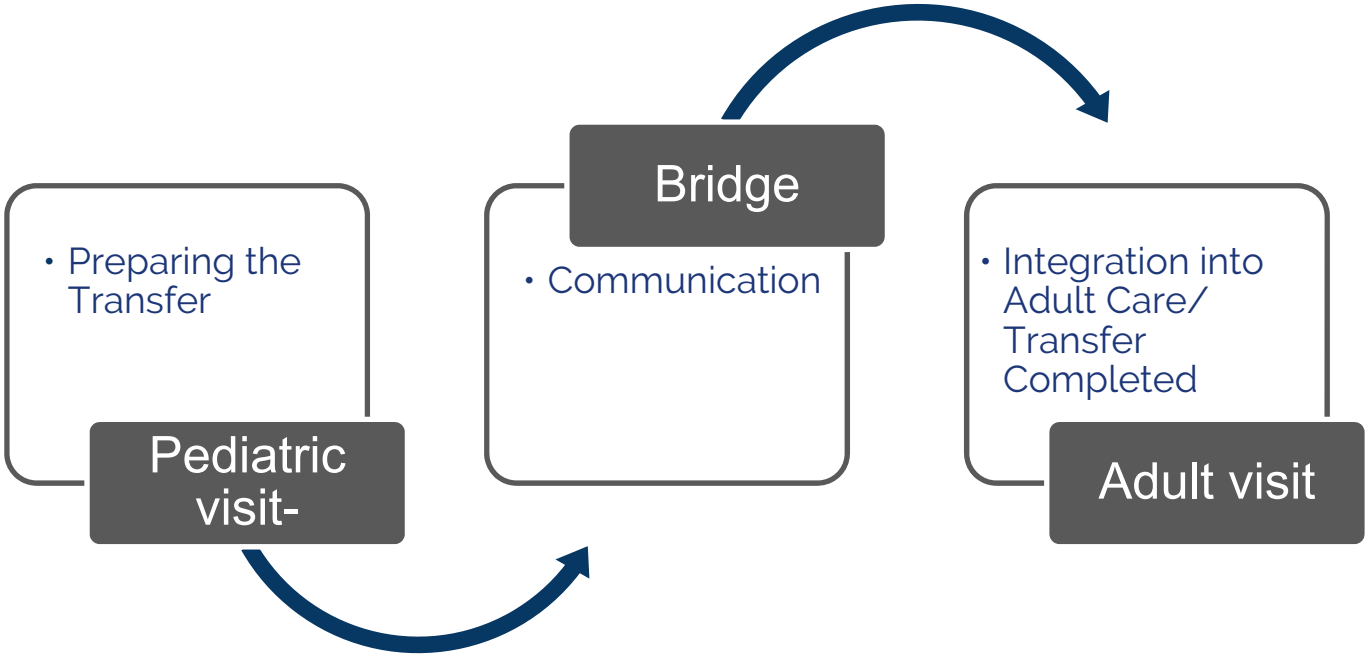
* Providers that care for youth/young adults throughout the life span could utilize both sets of core elements without the transfer process components

Transfer Process to Integrate into Adult Health Care



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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

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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

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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

Adult Practice Welcome letter Content (cont.)

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

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Adult Practice FAQ info

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.

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Introductory Remarks

Shirley Payne, MPH

Director, Children's Special Health Care Services

Indiana State Department of Health

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Introduction into Adult Care

Mary R Ciccarelli, MD

Indiana University School of Medicine

May 2018

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Center for Youth and Adults with Conditions of Childhood

Indiana Title V program - Statewide Transition Service

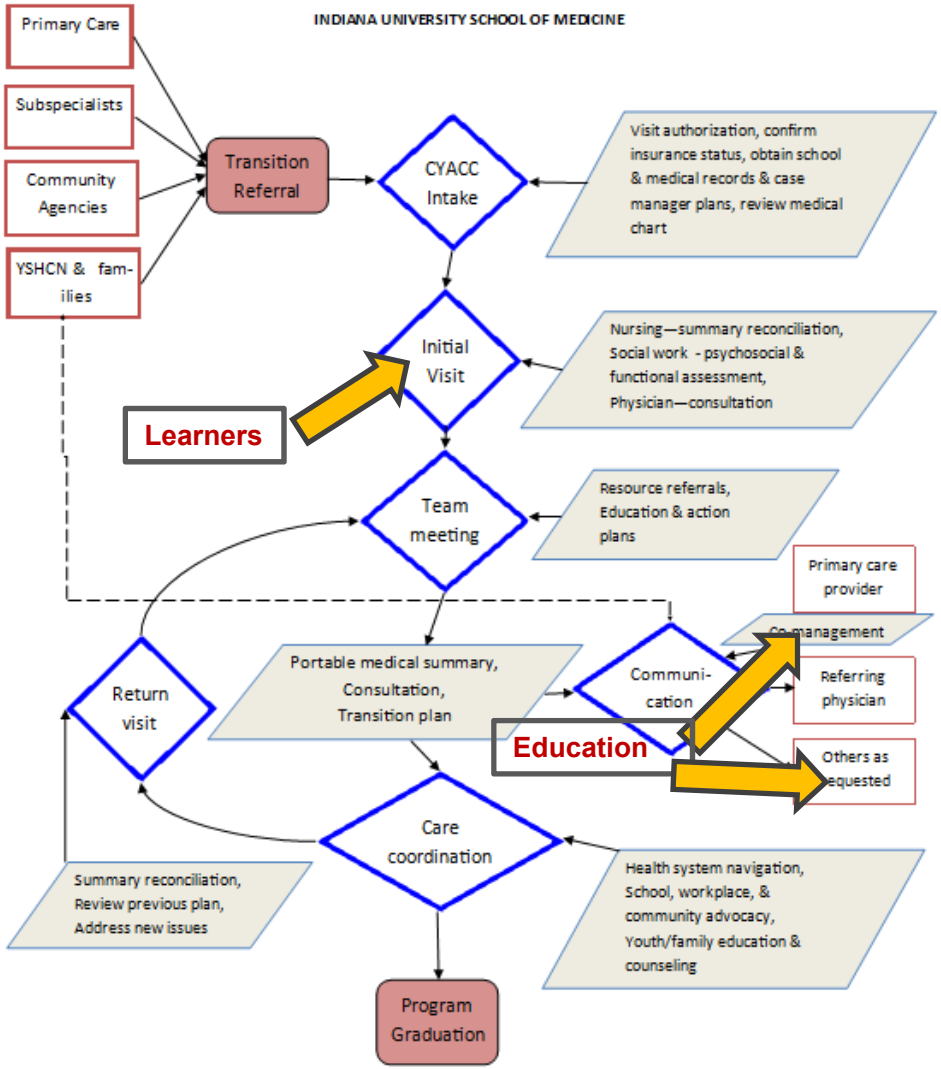
Team – Social workers, nurses, med-peds physicians, parent/youth representatives

- 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

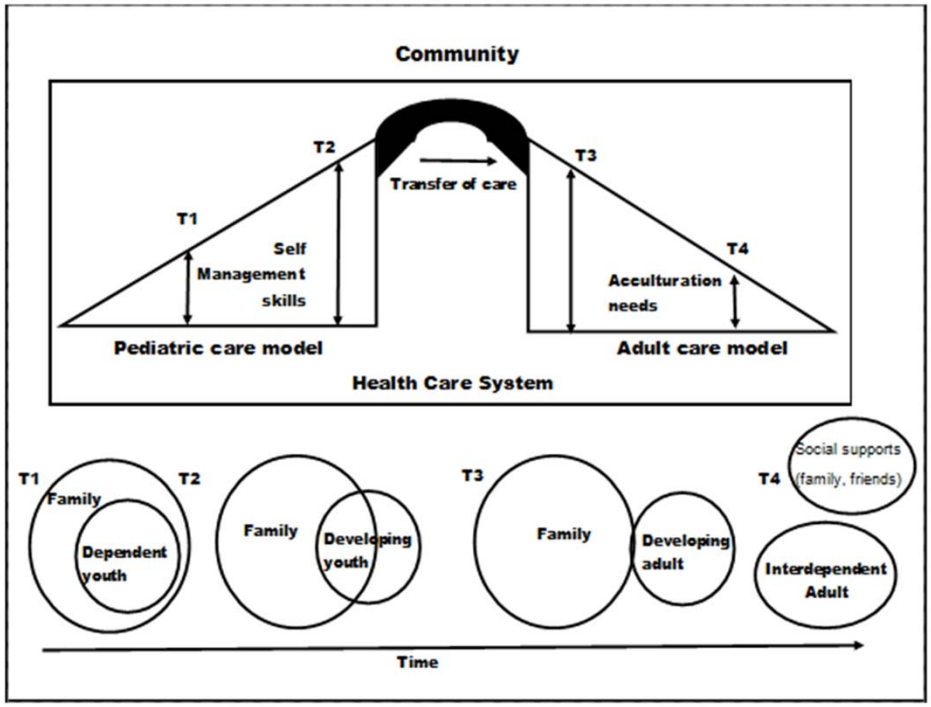
CYACC goals

- 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

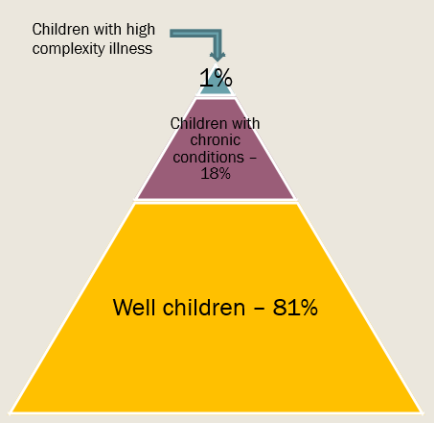


Transition planning action items

- 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



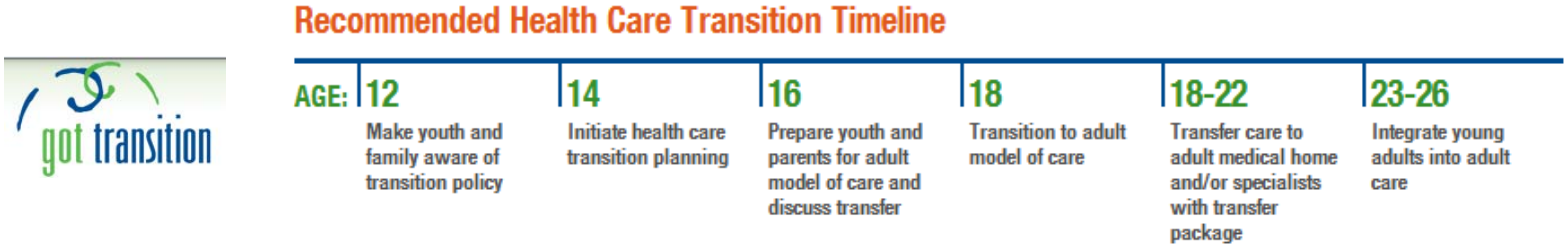
- School/work
- Independence living
- Community participation
- Legal issues/finances



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%

Rezaee ME. Prev Chron Dis, 2015

- Obesity
- Allergies
- Development behavior issues

Adult Medicine

"Autonomy" as an adult in decision making

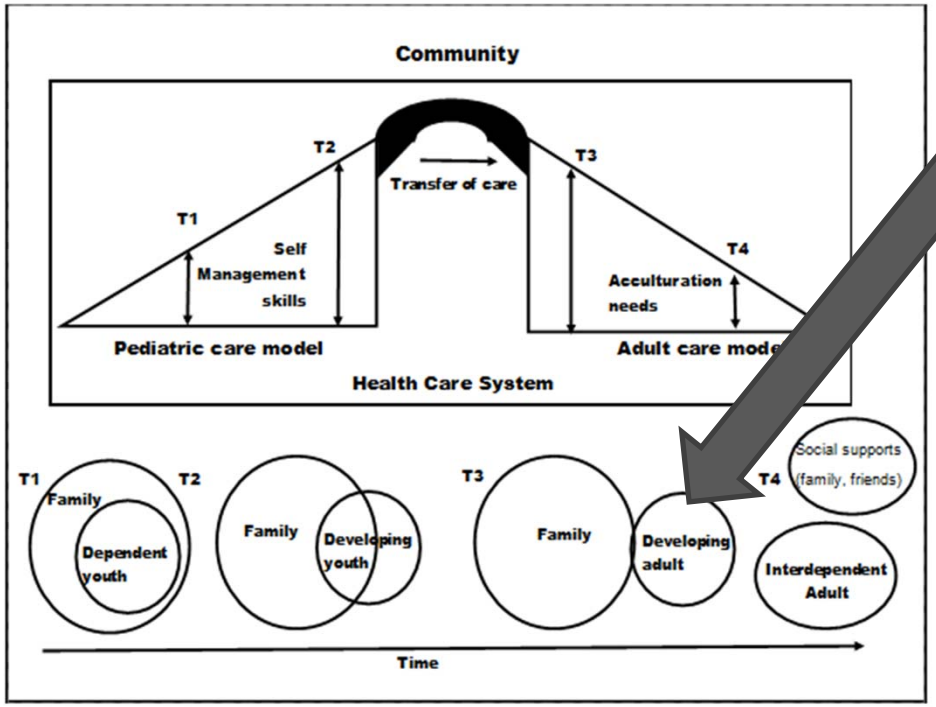
33% visits for routine chronic care

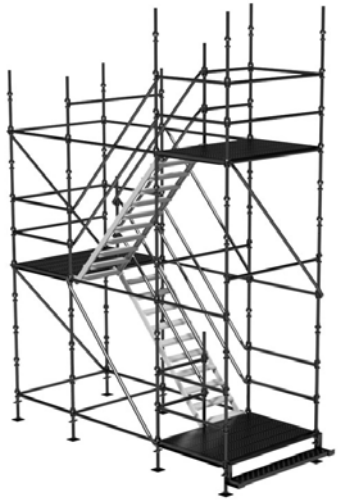
- Hypertension 32.5% ages 45-64
- Hyperlipidemia 21.5%
- Arthritis 17.3%
- Diabetes 13.9%
- Depression 12.2%
- Asthma 5.7%

NAMCS, 2012

Scaffolding supports

"Railings on the transition bridge"

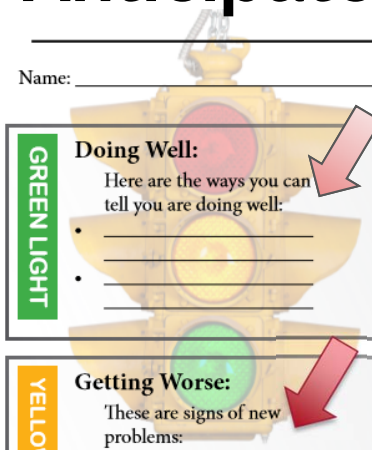




Anticipatory Adherence Counseling

ACTION PLAN

Name: _____ Date: _____



GREEN LIGHT

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:

_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____

YELLOW LIGHT

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:

_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____

RED LIGHT

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 and urgent problem and you need help today!
Doctor: _____
Phone: _____

Reasons to get emergency medical help:

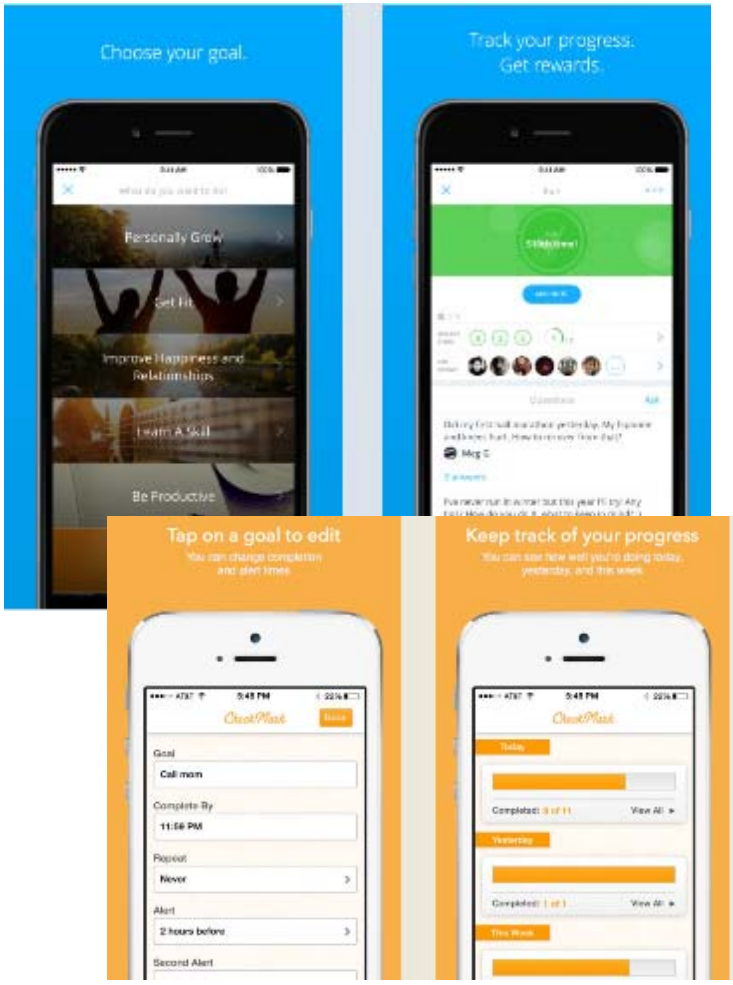
- _____
- _____
- _____

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

Who else do you need to tell? _____

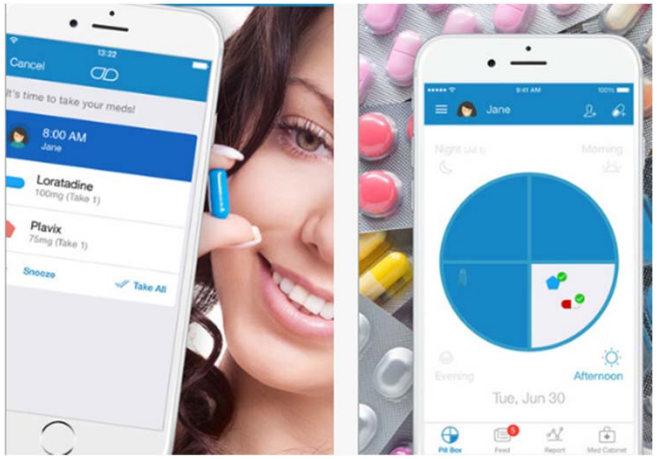
Health habit smartphone apps

Coach me & Checkmark goals



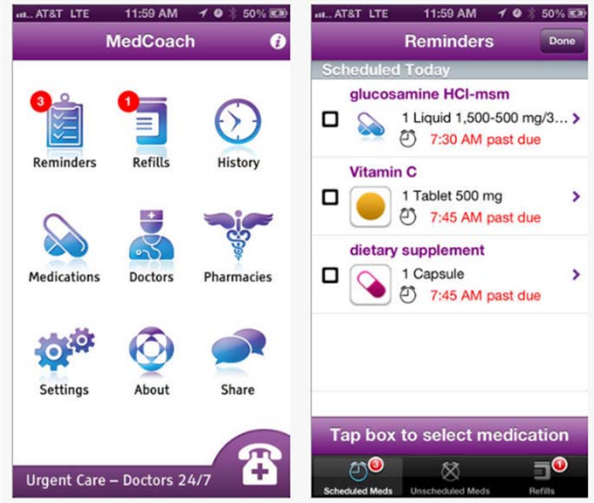
Way of Life

Self-management smart phone apps

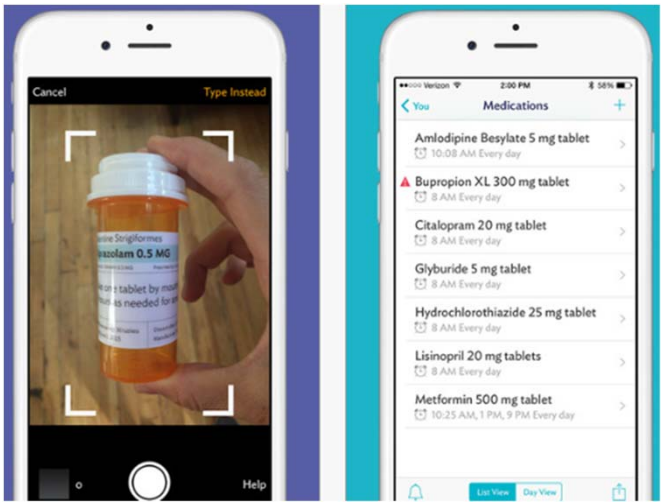


Medisafe

MedCoach



carezone



Smartphone – In Case of Emergency

- iPhone's Settings
  - SOS
  - Emergency Contacts in Health
  - Create Medical ID
- Android
  - QuickICE app
- http://incaseofemergency.org
- http://www.ice4autism.com/

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/

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

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
http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/ComplexityScale.pdf

LEVEL OF SUPPORT

DIMENSION	1 (Minimal)	2 (Limited/Intermittent)	3 (Extensive)
1. Health	Health status stable, routine preventive care, may see specialist annually	Health status generally stable, regular office visits to review management, periodic consultation with 1 or more specialists	Health status unstable, frequent office visits, regular ER visits or hospitalization, frequent consultations with 1 or more specialists
2. Family	Family status stable, no major environmental stresses, traditional social supports present and utilized	One or more stresses may be present, family requires occasional support from office and other community resources	Multiple major stresses are present, family resources are overwhelmed, extensive community support needed or major concerns about care giving environment
3. Behavioral and Mental Health	Behavior health status is stable, routine anticipatory guidance	Regular office visits to review management or regular consultation/counseling with mental health providers	Behavioral health status is unstable, extensive supports from office and community professionals, may require day treatment program or in-patient treatment
4. Education	Routine monitoring of developmental/school progress, regular classroom with minimal support	Child has IFSP, IEP or 504 plan, most of child's needs are met in regular classroom, may require 1 special health procedure at school	Extensive support required, full time aide or special class for most of the day, or multiple special health procedures in educational setting
5. Special Issues	Child and family follow through with recommendations readily, limited need for decision supports, no or few cultural factors impact care, child/family proactively manage care	Child and family require extra time to understand healthcare rec's, regular need for decision supports, translator required for appts, occasional missed appts.	Extensive need for decision supports and care reminders, cultural issues are major barrier to care, limited capacity for self-management, or major disagreements with the care plan

Nickel, 2011

Total Score _____

Medically complex patient shared plan of care

SHARED CLINICAL PLAN OF CARE

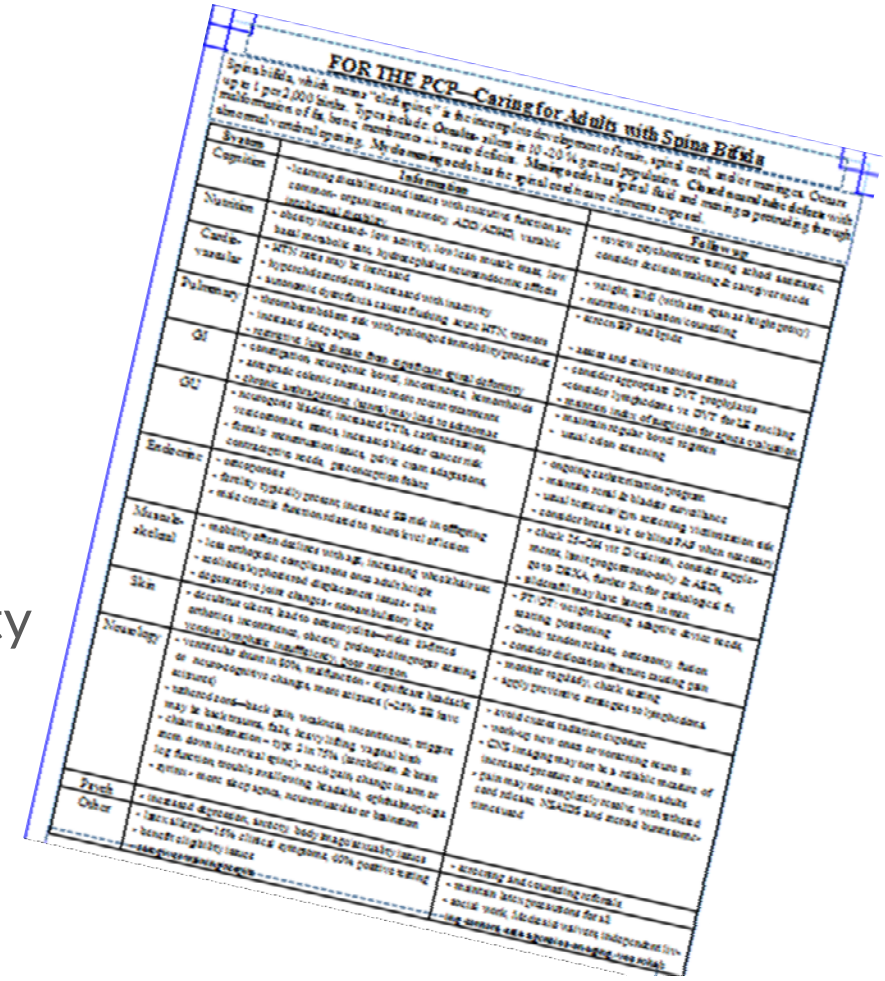
Name:_____ **DOB:**_____ **MRN:**_____ **Caregiver:**_____

Diagnosis/Issue	Last updated:	Principal clinician	Clinical team members	
Current Goal			Treatment plan	
Flare symptoms	Flare management		Emergency symptoms	Emergency management

Diagnosis/Issue	Last updated:	Principal clinician	Clinical team members	
Current Goal			Treatment plan	
Flare symptoms	Flare management		Emergency symptoms	Emergency management

Receiving office supports

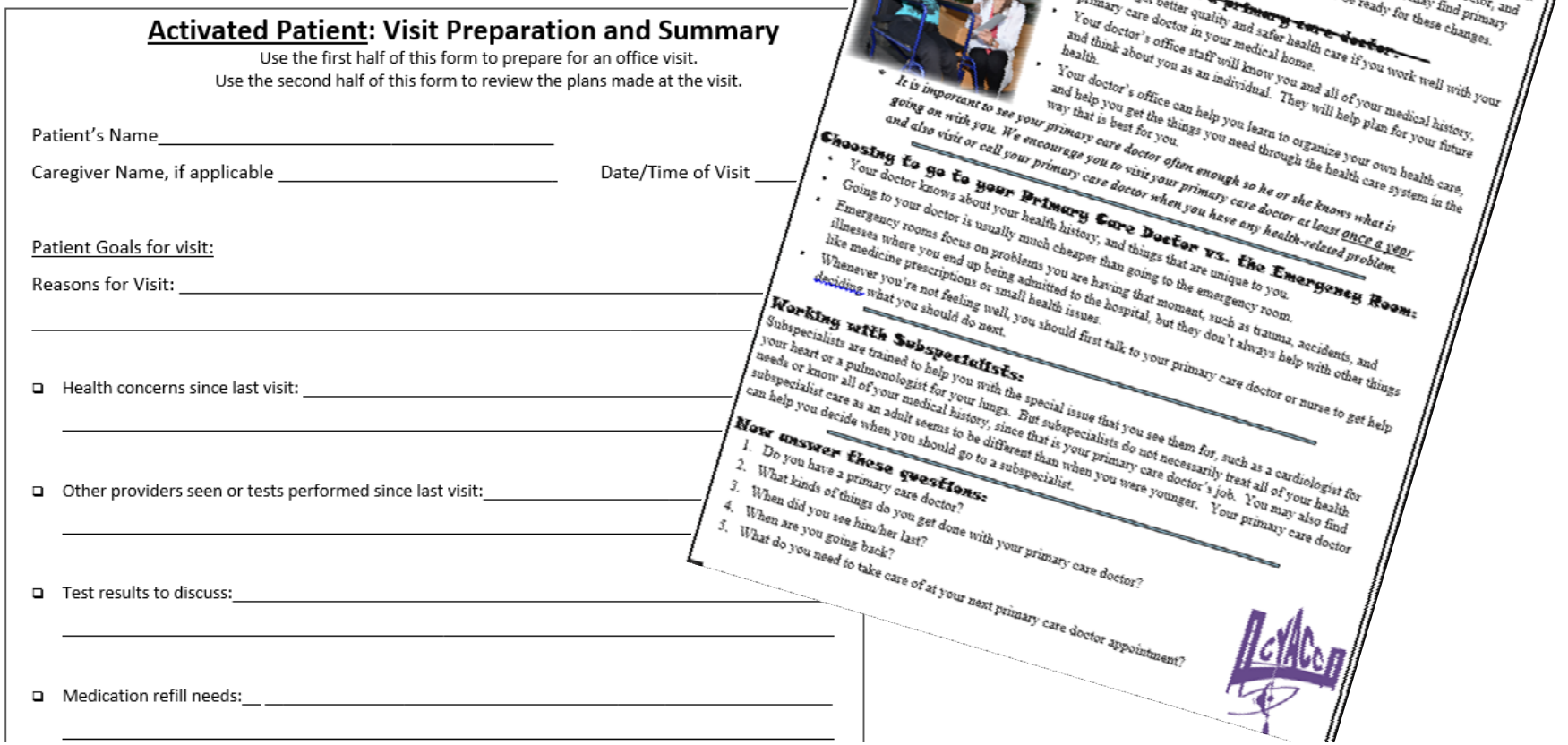
- Policy & Office FAQs
- Receipt of transfer packet
- Office tools
- Care Team education handouts
- Health system and community resources



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

Adult practice supports



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_____

Caregiver Name, if applicable _____ Date/Time of Visit ____

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 CYACC transition program wants to help you get ready to work well with your primary care doctor, and to 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.

Reasons to have a primary care doctor.

- 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. We encourage you to visit your primary care doctor at least once a year and also visit or call your primary care doctor when you have any health-related problem.*

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

- Your doctor knows about your health history, and things that are unique to you.
- Going to your doctor is usually much cheaper than going to the emergency room.
- Emergency rooms focus 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 medicine prescriptions or small health issues.
- Whenever 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 issue that you see them for, such as a cardiologist for your heart or a pulmonologist for your lungs. But subspecialists do not necessarily treat all of your health needs or know all of your medical history, since that is your primary care doctor's job. You may also find subspecialist care as an adult seems to be different than when you were younger. Your primary care doctor can help you decide when you should go to a subspecialist.

Now answer these questions:

1. Do you have a primary care doctor?
2. What kinds of things do you get done with your primary care doctor?
3. When did you see him/her last?
4. When are you going back?
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 must adapt to the 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 improved health outcomes and more appropriate health care utilization. (Hibbard JH. Health Affairs, Feb 2013).
- Providers should assess self-management and patient activation as part of transition readiness. Direct patients to self-management supports (systematic education and interventions to increase patients' skills and confidence in managing their health problems—IOM, 2002).

Using a Transition Readiness Tool

- The TRAQ is a validated transition readiness tool. http://hsc.ufl.edu/jaxhats/traq. Sample questions:
  - **Do you call the doctor's office to make an appointment?**
  - **Do you follow up on any referral for tests or check ups or labs?**
  - **Do you arrange for your ride to medical appointments?**
  - **Do you call the doctor about unusual changes in your health?**
  - **Do you know what your health insurance covers?**
  - **Do you fill out the medical history form, including a list of your allergies?**
  - **Do you keep a calendar or list of medical and other appointments?**
  - **Do you answer questions that are asked by the doctor, nurse or clinic staff?**
  - **Do you ask questions of the doctor, nurse or clinic staff?**
  - **Do you take medications correctly and on your own?**
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  - **What do you know about… (the condition)?**
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- Advise: Encourage patients to actively manage their condition. Give patients information about their conditions and treatment. Review their history to help them learn what they don't know about their medical history. Use medication reconciliation and "repeat back" techniques to verify understanding. Identify health coaches from the team or community to provide education to help patients self-care.
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  - Encourage the young adult recognize how one's support system (family and friends) may be asked to help.

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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
- Developmental Disabilities Act
  - **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 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?

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Upcoming Title V Care Coordination Webinars

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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!

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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

EMAIL
mciccare@iu.edu
pwhite@thenationalalliance.org

FACEBOOK PAGE
HealthCareTransition

TWITTER
@gottransition2

_____ ACTION PLAN

Name: _____ Date: _____

GREEN LIGHT

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:

_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____

YELLOW LIGHT

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:

_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____

RED LIGHT

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 and 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? _____

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_____

Caregiver Name, if applicable _____ Date/Time of Visit _____

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:__ _____

  _____

- ❑ Equipment needs:_____ _____

  _____

Physician Plans at visit:

_____

_____

- ❑ Labs/Testing planned: _____

  _____

- ❑ Medication/Treatment changes: _____

  _____

- ❑ Referrals recommended:_____

  _____

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 must adapt to the 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 improved health outcomes and more appropriate health care utilization. (Hibbard JH. Health Affairs, Feb 2013).
- Providers should assess self-management and patient activation as part of transition readiness. Direct patients to **self-management supports** (systematic education and interventions to increase patients' skills and confidence in managing their health problems—IOM, 2003).

Using a Transition Readiness Tool

- The TRAQ is a validated transition readiness tool. http://hscj.ufl.edu/jaxhats/traq. Sample questions:
  - **Do you call the doctor's office to make an appointment?**
  - **Do you follow up on any referral for tests or check ups or labs?**
  - **Do you arrange for your ride to medical appointments?**
  - **Do you call the doctor about unusual changes in your health?**
  - **Do you know what your health insurance covers?**
  - **Do you fill out the medical history form, including a list of your allergies?**
  - **Do you keep a calendar or list of medical and other appointments?**
  - **Do you answer questions that are asked by the doctor, nurse or clinic staff?**
  - **Do you ask questions of the doctor, nurse or clinic staff?**
  - **Do you take medications correctly and on your own?**
  - **Do you know what to do if you are having a bad reaction to your medications?**
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Working on Self-Management Skills Building

- **Assess:** find out about the patient's health-related beliefs, behavior and knowledge.
  - **What do you know about… (the condition)?**
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Things to ask my doctor:

Current Symptoms:

The medications I am currently taking:

Instructions from my doctor:

Follow-up appointment:
Date: _____ Time: _____
Location: _____

If I have a problem or questions, I should call:

→ The change I want to make is: (be very specific, what, when, how?)

→ My goal for the next month is:

→ How convinced are you that this is the right work for you:

☹ 😐 ☺

0 Totally unconvinced 1 2 Unsure 3 4 5 Somewhat convinced 6 7 8 Very convinced 9 10 Extremely convinced

→ The steps I will take to reach the goal:

1. _____
2. _____
3. _____

→ The things that will make it hard to reach the goal:

1. _____
2. _____
3. _____

→ The ways I can overcome those things that might get in the way:

→ My confidence that I can reach my goal:

☹ 😐 ☺

0 Not confident at all 1 2 Unsure 3 4 5 Somewhat confident 6 7 8 Very confident 9 10 Extremely confident

GREEN ZONE

Doing Well

- No cough, wheeze, chest tightness, or shortness of breath during the day or night
- Can do usual activities

And, if a peak flow meter is used,

Peak flow: more than _____
(80 percent or more of my best peak flow)

My best peak flow is: _____

Take these long-term control medicines each day (include an anti-inflammatory).

Medicine	How much to take	When to take it
Before exercise ❒ _____	❒ 2 or ❒ 4 puffs _____	5 minutes before exercise

YELLOW ZONE

Asthma Is Getting Worse

- Cough, wheeze, chest tightness, or shortness of breath, or
- Waking at night due to asthma, or
- Can do some, but not all, usual activities

-Or-

Peak flow: _____ to _____
(50 to 79 percent of my best peak flow)

First → **Add: quick-relief medicine—and keep taking your GREEN ZONE medicine.**

_____ (short-acting beta$_2$-agonist) ❒ 2 or ❒ 4 puffs, every 20 minutes for up to 1 hour ❒ Nebulizer, once

Second → **If your symptoms (and peak flow, if used) return to GREEN ZONE after 1 hour of above treatment:**
❒ Continue monitoring to be sure you stay in the green zone.

-Or-

If your symptoms (and peak flow, if used) do not return to GREEN ZONE after 1 hour of above treatment:
❒ Take: _____ (short-acting beta$_2$-agonist) ❒ 2 or ❒ 4 puffs or ❒ Nebulizer
❒ Add: _____ (oral steroid) mg per day For _____ (3–10) days
❒ Call the doctor ❒ before/ ❒ within _____ hours after taking the oral steroid.

RED ZONE

Medical Alert!

- Very short of breath, or
- Quick-relief medicines have not helped, or
- Cannot do usual activities, or
- Symptoms are same or get worse after 24 hours in Yellow Zone

-Or-

Peak flow: less than _____
(50 percent of my best peak flow)

Take this medicine:

❒ _____ (short-acting beta$_2$-agonist) ❒ 4 or ❒ 6 puffs or ❒ Nebulizer

❒ _____ (oral steroid) mg

Then call your doctor NOW. Go to the hospital or call an ambulance if:
- You are still in the red zone after 15 minutes AND
- You have not reached your doctor.

DANGER SIGNS
- **Trouble walking and talking due to shortness of breath**
- **Lips or fingernails are blue**

→
- **Take ❒ 4 or ❒ 6 puffs of your quick-relief medicine AND**
- **Go to the hospital or call for an ambulance _____ (phone) NOW!**

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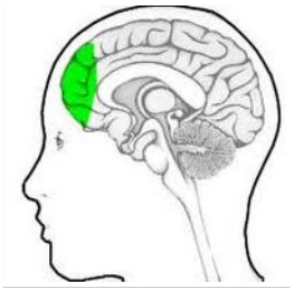

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ABOUT ME: Call me "_____"

Approximate Developmental Age:		**Photo:**
How I communicate:		
What I like and what makes me happy:		
What stresses me:		
Behaviors when I'm stressed:		
How to help me when I'm stressed:		
My legal decision maker:		
My other caregivers:		

WHEN I AM CONTENT	WHEN I AM STRESSED
Face: **Eyes:** **Jaw/tongue:** **Skin:**	
Sounds: **Speech:**	
Habits: **Comfortable Distance:**	
Posture: **Pulse:** **Breathing:** **Sleep:** **Appetite:** **Eating pattern:**	
Adapted from DISDAT tool at https://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat.aspx	

Patient Name:_____

Preferred Disability Accommodations

Utilize an orientation board in patient room which says: *"Patient needs accommodations for activity and interventions. Please see nurse for hospitalization plan."*

Emergency Plan:
Code status /Advance Directives:
Allergies/Precautions:
Vital signs accommodations:
Activity:
Nursing - Skin Care/Hygiene needs:
Nursing - Positioning/Transferring:
Nursing - Toileting/Menses:
Nursing - Supervision/Attendant Care:
Nursing - Communication/Sensory/Vision/Hearing:
Diet/Feeding:
Medication Administration:
Lab/procedure accommodations:
Special devices/Implanted devices:
Special sleeping preferences:
Special safety concerns:
Respiratory needs:

Health Habits & Daily Rules

Use daily rules to help you stay healthy,
especially if you are not good at feeling or using your own body messages.

Times to Eat

My breakfast time: _____

My lunch time: _____

My snack time: _____

My dinner time: _____

Food & Drink

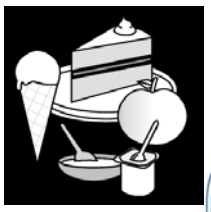
I eat _____ servings of fruit every day.

I eat _____servings of vegetables.

I eat _____ servings of calcium foods.

I eat _____ servings of protein.

I fill my plate once a meal.



I pick one day a week (_____) for a treat.

I drink _____ glasses of water.

I drink _____ glasses of other drinks too.

Physical activity

I do this exercise: _____ for _____ minutes _____ times a week.

Bathroom — I go

when I get up _____,

after breakfast _____,

after lunch _____,

after work/school _____,

after dinner _____,

before bedtime _____.

Clean your body

I wash my hands before I eat, and after the bathroom.

I brush my teeth 2x, mornings  and evenings. 

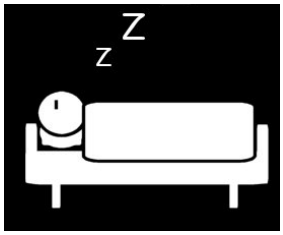
I shower every _____ day(s).

I wash my hair every _____ day(s) 

I put on clean clothes every day.

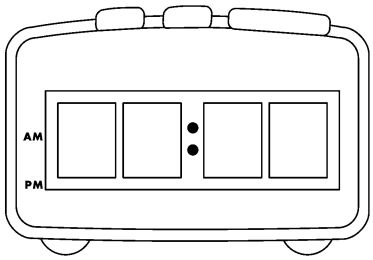
I cut my finger & toe nails every _____ week (s).

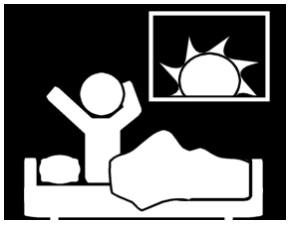
Sleep



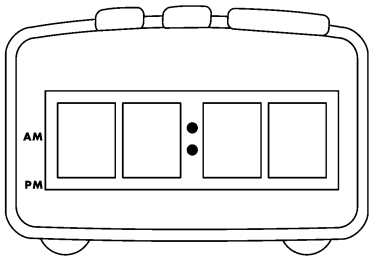
.

My bedtime is:





My wake up time is :



Supporting Health Habits

For caregivers of individuals with learning difficulties (LD) or intellectual disabilities (ID)

Daily Rules

- **For activity**
- **For eating**
- **For hydration**
- **For hygiene**
- **For sleep**
- **For toileting**

Supporting the person with mild LD/ID—Maximize actions the person can do on their own

1. Teach and then entrust the person to be in charge of their own daily health rules. Set an example by following healthy daily rules yourself.
2. Teach things to watch for to recognize when the usual rules don't apply.
3. Be present to support problem solving for those unusual days. Teach that asking for help is something that everyone needs sometimes.

Supporting the person with moderate ID— Find a balance between actions by the person and their caregivers

1. Teach the person about their own daily health rules. Encourage them to do as much as possible and safe on their own. Provide enough oversight to know how the rules are followed. Set an example by following healthy daily rules yourself.
2. Review periodically to help reinforce the rules. Teach that sometimes the rules don't apply and that everyone needs help sometimes.
3. Recognize and suggest when the usual rules may not apply. Provide oversight and solutions for what to do on unusual days.

Supporting the person with severe/profound ID - For most actions, caregivers need to be in charge

1. Teach the person about their daily health rules. Support them every day, use helpful reminders, provide needed supports, avoid nagging. Set an example by following healthy daily rules yourself.
2. Observe day to day activities and encourage info sharing, while still considering privacy as able. For example, "tell me when you go to the bathroom, so I can help you stay healthy."
3. Recognize unusual days and create solutions for what to do.

My health goals

- I want to eat healthy foods and portions and drink enough fluids every day.
- I want to keep my body clean (washing up regularly) and active (exercising at least 3 times a week).
- I want to take care of my body needs, going to the bathroom regularly.
- I want to get enough sleep to be well-rested every day (7-9 hours).

Center for Youth and Adults with Conditions of Childhood cyacc@iupui.edu

Sample Welcome and Orientation of New Young Adults

Six Core Elements of Health Care Transition 2.0

[Adult Practice Name] is pleased to welcome you into our practice. Our practice places young adults in the center of their own health care. This means that our providers do not discuss your care with anyone else unless you ask that we do. We understand that some young adults involve family and close friends in their health care decisions. To allow others to be involved in your health care decisions you will need to complete a signed consent. These forms are available at the clinic. For young adults unable to provide consent, we will need legal documentation about decision-making arrangements.

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 and answers 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)?

A:

Q: Are services confidential?

A:

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

A:

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

A:

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

A:

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

A:

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

A:

Q: What insurance is accepted?

A:

Q: How much do visits cost?

A:

Q: What should I bring for my first appointment?

A:

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)?

A:

got transition

PRACTICE RESOURCE – NO.3
JULY 2015

Integrating Young Adults with Intellectual and Developmental Disabilities into Your Practice: Tips for Adult Health Care Providers

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In General to Prepare Your Office and Staff

1. Consider an in-service training or "lunch and learn" session(s) for all staff about caring for individuals with intellectual and developmental disabilities (ID/DD), including an understanding of supported decision–making/guardianship options, "people first" language, and ID/DD not as a disease, but as a sometimes challenging life experience, which may often include co-existing or condition specific health problems or risks.
2. Consider identifying a staff person as the "office champion" for this population -- maybe someone who has a family member with ID or DD -- who may keep the office supplied with local and regional resource information, workshop availability, and related health news. This individual may also be asked to provide regular feedback on the practice's performance in caring for this population.
3. Organize a "walkthrough" or "ride through in a wheelchair" of the office for all staff -- from the parking lot through an entire hypothetical office visit -- to understand the challenges that patients may experience and to ascertain areas for improving access.
4. Consider inviting a few young adults with ID/DD and parents/caregivers to participate in a focus group or a transition improvement process in your practice.

Prior to the First Visit

1. Review the tools available in the Six Core Elements of Health Care Transition ("Integrating Young Adults into Adult Health Care") found at www.gottransition.org and adapt the core elements to this population's needs. For example:
    a. Develop a transition policy or statement, with input from young adults with ID/DD, that describes your practice's approach to welcoming young adults and, if needed, their

caregivers. This can be shared with all staff and discussed with young adults and their caregivers at their first visit. (See sample policy from Six Core Elements, which can be customized for your practice.)

b. Create an office registry for this population in order to track individual progress related to receipt of their current medical records, welcome and orientation to your practice, clarification of shared decision-making status and implications (guardianship, powers of attorney, and consent to share personal health information), self-care assessment, and plan of care. The registry can also be used to track the status of the population's health, preventive care status, and health risks. (See sample registry from Six Core Elements.)
c. Identify the clinicians in your practice that are interested in caring for young adults with ID/DD.
d. Develop a brief welcome letter and frequently asked questions (FAQs) about your practice with input from young adults and caregivers, and post the content on your website. (See sample welcome letter and FAQs from Six Core Elements).

2. Obtain health records from previous provider(s) including recent care plans, active problem lists, medication lists, and health care transition readiness/self-care assessment status.
3. Ask the pediatric provider to send you information about the youth's specific childhood-onset/congenital conditions (e.g. Down syndrome, Fragile X syndrome) associated with the patient's intellectual disability, including any existing preventive care guidelines for such conditions.
4. Ascertain shared decision-making status and implications (guardianship, powers of attorney, and consent to share personal health information).
5. Ascertain the young adult's ability to communicate and communication method if other than verbal speech, and identify use of any other assistive technology, including mobility devices. Recognize that individuals with ID/DD who use verbal communication may do so in atypical ways or with unexpected meanings.
6. Arrange for staff to inquire prior to the first visit if there are any special accommodations that will be necessary during the visit.
7. Schedule adequate time for a successful the first visit taking into consideration assistive devices for mobility and/or communication, presence of caregivers and others, and need to orient the new patient to your practice and to adult health care in general. Understand that some patients with ID/DD may require several visits to accomplish the goals that might usually be met in one visit for other patients.

During the Visit

1. Treat the patient as an adult regardless of level of intellectual disability – greet the patient first, speak and direct questions to the patient even if a caregiver provides responses. Encourage the highest level of involvement of the patient in his or her care.
2. Ascertain name, contact information, and role or relationship to the patient of any caregivers and others present at the visit.
3. Explain what will happen during the visit and invite caregiver to "translate" if necessary.
4. Provide an orientation to the practice or clinic to patient and caregiver, including methods for 24/7 access to care, access to any electronic patient portal, process for prescription renewals and for referrals.
5. Demand of yourself and your staff the same quality and process of care that you would provide to a patient without intellectual disability (all vital signs recorded, complete history obtained,

complete physical examination conducted, same treatment recommendations delivered, all preventive care and screening measures provided). At times, the elements of a process of care may require several office visits.

6. Continue the use of a care plan identifying status of and responsibility for action items.
7. Determine the status of all specialty care with respect to the process of transition from pediatric to adult specialists. Some specialty care may need to remain in the pediatric domain until appropriate adult specialists are identified.
8. Continue a process of readiness/self-care assessment and education for the highest possible level of self-management. (See sample readiness/self-care assessment and plan of care forms in Six Core Elements.)

After the Visit

1. Consider more frequent than annual visits even in someone without secondary chronic conditions in order to strengthen the relationship more quickly and to familiarize the patient with the office. The best care for any patient is relationship-based.
2. Consider a follow-up telephone call from a clinical office staff member to review plan of care, medications, and procedures for accessing the office.
3. Follow-up with the prior pediatric care provider team to thank them for the referral, confirm that the patient has arrived in your care, clarify any questions arising from the visit, and ascertain availability of the pediatric care team for future "reverse consultations."
4. Consider a process for eliciting feedback about the first visit and the patient's and caregiver's experience of the transition process from pediatric to adult care. (See sample transition feedback survey in Six Core Elements).

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