

Approaches to Transitioning Youth and Young Adults from Pediatric to Adult Health Care Systems

Sponsored by the Health and Disability Special Interest Group (SIG)

In collaboration with ITAC



Indiana University **Center for Youth and Adults with Conditions of Childhood**

Services of a Transition Support Program



Riley Hospital for Children
Indiana University Health



SCHOOL OF MEDICINE
INDIANA UNIVERSITY

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Director, CYACC

October 17, 2011

Objective

- Describe services of a statewide transition support program
- Long-term goals for Indiana YSHCN:
 - Provide access to eligible and needed services
 - Demonstrate consumer satisfaction in transition process
 - Improve health outcomes through the transition
 - Improve quality of life of young adults with chronic conditions of childhood, including participation in adult life



Prelude to service delivery

1. Identify local transition needs
2. Seek stakeholders - advisory group, funders and collaborators
3. Develop mission, values, business plan, funding sources
4. Plan and construct model

Needs Assessment

- Dyson Community Pediatric Training Initiative
 - IUSM pediatric residency
 - About Special Kids (IPIN) parent-to-parent
 - AAP CATCH resident grant
 - Indiana MCH needs assessment grant
 - Retreat of stakeholders
- *MISSION: “Steering YSHCN toward successful adult life”*
 - *Person-centered, family-centered*
 - *Promote self-advocacy, community Inclusion, medical home, system change*

Funding sources

- Inadequate clinical revenue
 - Enhanced reimbursement
 - Primary care chronic disease management
 - Maternal Child Health Title V core outcome 6
 - Department of Pediatrics
 - Children's hospital
 - Underserved programs – county hospitals, community health centers
 - State agencies - DOE, Medicaid, Division of Disabilities

CYACC Service Delivery

- Opened in 2006
 - Collaborating with medical home
 - Consultation & care coordination
 - YSHCN ages 11-22
 - Across diagnoses
 - Chronic illness, physical and intellectual disabilities
 - Trans-disciplinary team
 - Social workers, Nurses, Physicians
 - Community advocates, Parent liaisons

Services

Intake

- Referral from family, PCP, specialists, community
- Obtain records – school, medical, case manager
- Office visit – reconcile medical summary, functional psychosocial assessment, medical consultation

Communicate

- Team meeting - referrals, portable medical summary, transition plan
- Report shared with youth, medical home, others
- Primary care education & co-management

Care coordinate

- Health system navigation
- School, workplace, & community advocacy
- Youth/family education & counseling
- Annual follow-up visit or program graduation

2010 Annual Report

- Referrals N = 275
 - 18% family, 25% PCP, 54% subspecialist, 3% community agency
- Office visits N = 305
 - 77% Medicaid
 - 13% Title V
- Average age = 17
 - Range 11-52

- Caucasian 58%
- African American 28%
- Hispanic 7%
- Other 7%

Diagnoses

- Cerebral Palsy 26%
- Dev Delay 14%
- Autism 13%
- Spina Bifida 10%
- Down syndrome 8%
- Other 29%

Service Delivery

Category	% served
Preventive care – routine or disease-specific	50
Clarification/simplification of treatment plan	48
Parenting issue	48
Care coordination with other providers	46
Health care financing	40
Self management needs	38
Behavioral issue	32
New physician sought –primary or subspecialty	30
Decision making capacity	26
School issue	24
Work issue	24
New diagnosis made	14

Educational Outreach

- Youth programs
 - Be Your Own Boss
 - Down Syndrome Welcome to Adult Life
- IUPUI Student interest group
- IUSM Residency – Peds and med -peds
 - Lectures
 - Clinic experience in Community Peds rotation
 - Service Learning projects
- IUSM IM department curriculum development grant
- Community PCP CME-Caring for persons with ID
- New Transition Program Support for university programs

Lessons learned

- Patient and family centered approach
 - team members, youth and parents
- Stakeholders and advisory groups
 - new collaborations, funding sources, service delivery improvements
- Education
 - transition fellowship
 - websites, community programs, curricula, health professional internships
- Effectiveness
 - Satisfaction survey
 - Longitudinal outcome measurement

THANK YOU!

- CYACC Team
 - Erin Gladstone
 - Steve Koch, PhD
 - Sandra Love, RN
 - Brittany Mak
 - Elise Montoya, RN
 - Hannah Ricker
 - Christina Rogers, MSW
 - Kerstin Sobus, MD
 - Nancy Swigonski, MD, MPH
 - Jane Taylor-Holmes, MSW
 - Katie Weber, MD
 - Jason Woodward, MD
- IUSM Dept. of Pediatrics
- ISDH MCH
- Wishard Health Services
- IUMG-PC
- accessABILITY, Inc
- About Special Kids
- IUSM Dept. of Medicine
- MDwise Medicaid
- Indiana Disabilities, Aging and Rehab
- Indiana Institute on Disability and Community
- Hands in Autism
- IUSM Dept. of Public Health
- IUPUI School of Social Work

Transition of Care at duPont Hospital for Children

Cory Ellen Nourie, MSS, MLSP
Patient Transition Social Work Coordinator



Nemours/ AIDHC

- Wilmington, DE
- Department of Pediatrics for Jefferson Medical College in Philadelphia
- Patients primarily from DE, PA, MD, NJ
- 90,000 patient visits/year

Background

- Rule of 21– Mr. DuPont’s testamentary trust
- Transition Committee of Medical Staff in 2000
 - Physicians, social workers, parents, state agencies, UD/UCEDD
 - Met monthly

Background

- 2007 CDS (UCEDD) survey of AIDHC “graduates,” funded by DE’s Title V program
 - Poorly prepared for transition
 - No identified adult health care providers
 - No treatment summaries
 - No direct communication between pediatric and adult providers
 - Families did not want to leave AIDHC

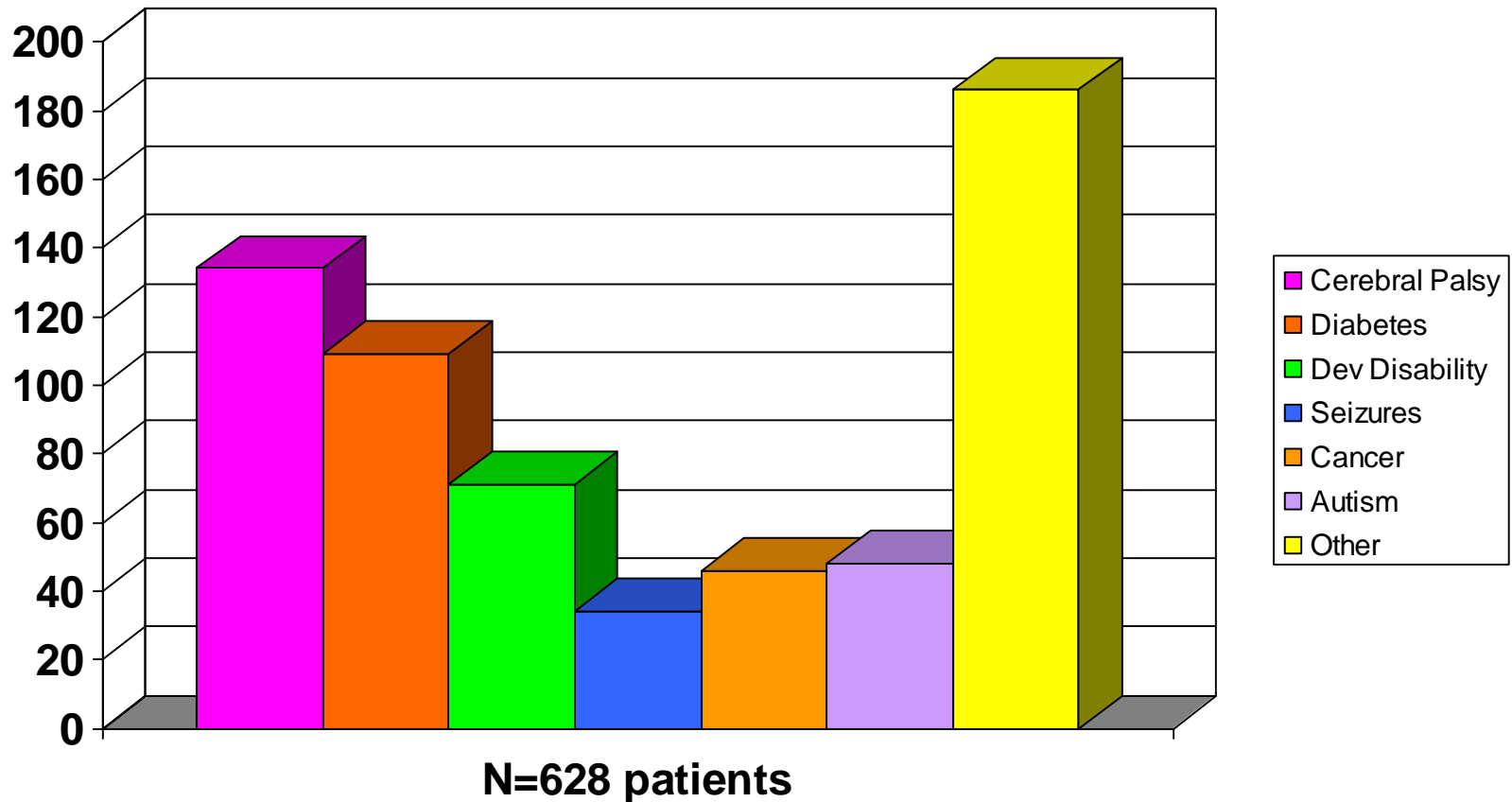
Transition Program- 2008

- 0.5 FTE senior pediatrician
- 1.0 FTE Social Work Coordinator
- 0.5 FTE administrative support

Assessment of current state

- Met with 30 different disease-specific and diagnosis-specific groups
- Survey of AIDHC generalists and specialists re: concerns
- Data query to assess how many patients impacted

Patients who will be 21 in 2014 by diagnosis



Educational Outreach

- Physicians, nurses, social workers, customer service associates
- Community providers
- Home health care agencies
- Schools
- Patients and families

Transition of Care Service

- Division of Transition of Care, Dept. Pediatrics
- Inpatient consultations
- Ambulatory appointments- started .5 day every other week; now 2 days/week
- 90 minutes visits- both physician and social worker present

TOC visit: Physician

- **Medication reconciliation**
- **Current/chronic medical issues**
- **Potential concerns re: current management**
- **Unrecognized medical problems**
- **Identifies potential adult pcp/specialists**
- **Anticipatory guidance re: adult health care**
- **Assessment of self-management skills**
- **Physical examination**

TOC visit: Social Work Coordinator

Assesses current status and future plans

Addresses:

- Legal guardianship/power of attorney
- Insurance changes
- Financial resources, estate planning
- Vocation

TOC visit: Social Work Coordinator

- Continuing education
- Residential plans
- Social and recreational life
- Assistive technology
- Transportation
- Self-management/ self-advocacy
- Home health care supports

At the end of the TOC visit

- Patient and family leave with resources
- Collaborative action plan created with defined tasks and responsibilities
 - Patient/family
 - Social Work Coordinator
 - Physician
- Follow-up: 3-12 months based on age, preparation, self-management skills
- Patient and family receive the medical summary note

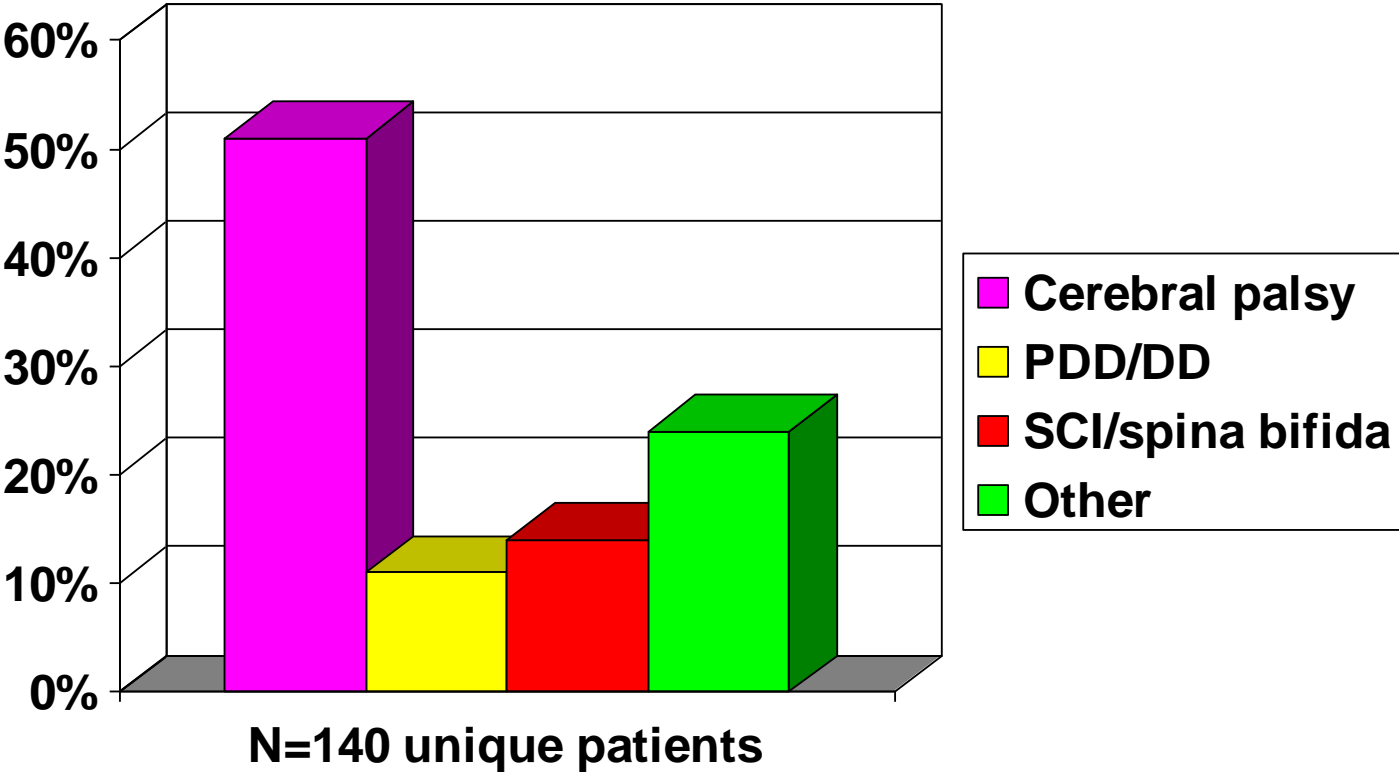
Billing

- Generally bill code: 99215
- Use primary diagnosis and major secondary diagnoses
- Reimbursement rate by third party payors/Medicaid similar to that obtained by other pediatric consultation services

TOC patients

- Average age is 19.4 years
- Average 4.8 subspecialists actively involved in care; 80% see orthopedics, 60% see neurology
- 57% of patients are dependent on some form of medical technology (g-tube, catheter, VP shunt, ventilator, etc)
- 67% have an intellectual disability
- 60% use a wheelchair
- 49% do not use any words to communicate

Primary Diagnosis of Patients in Transition of Care



Lessons Learned

- Patient population has extremely complex medical and psychosocial needs
- Challenging for TOC physician to rapidly assimilate understanding of patient's complex medical history and chronic problems
- Families have received little, if any, information about adult resources/community support services, legal issues, community programs
- Medical providers know little about these issues and generally do not address them with family

Lessons Learned

- 25% of patients referred to Transition of Care are not interested in making an initial appointment
- Most referrals come from Orthopedics, Urology, Neurology, Genetics
- TOC Physician's review of record and documentation of visit is extremely time-consuming

Lessons Learned

- Providers who refer patients to TOC expect TOC to now “own” transition issues
- Providers do not want to create comprehensive medical summaries because it is very time consuming and complicated, and because their effort is not reimbursed
- Program is resource intensive and will impact negatively on budget
- “For our patients, this team/program is not only valuable but vital. It is one of the greatest things we have to offer our families.”- APN

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The Youth Perspective

Stacey Milbern, Community Outreach Director
at the National Youth Leadership Network

The youth perspective!

- Identify all the work that is currently being done so we can know what to plan for.
 - Often times the support work done for youth with disabilities is done by one or two people and no one knows the extent of that work. A lot of the work is invisibilized. Let's identify those responsibilities or tasks so we can incorporate it all into a transition plan.
 - » Example: In the healthcare transition conversation, the example scenario is often at the doctor's office. But what about the other pieces – insurance to pay for doc's office? Paratransit to get to office?

The youth perspective!

- Healthcare transition requires a shift in roles. Adults must now move from being people responsible for us to our allies.
 - Think about what it means to be a disability ally. Challenge parents to think critically about how people with disabilities are treated and how they can challenge that ableism in their relationships.
 - Step back so young people can step up.
 - Support self-determination.
 - Encourage and partner with young person to formalize or build their support system.

The youth perspective!

- Create space for young people to make mistakes.
 - Understand that mistakes are how people learn. Youth with disabilities should be afforded the same opportunity to make mistakes.
 - Support authentic mentorship.
 - Distinguish difference between fear and reality. What safety nets do we need to create for young people to be able to make a mistake? What is us not wanting that person to be hurt?



AUCD Webinar
October 17, 2011

W. Carl Cooley, MD
Co-Director, Got Transition
Medical Director, Center for Medical Home Improvement
Adjunct Professor of Pediatrics, Dartmouth Medical School

OPENING DOORS TO A HEALTHY FUTURE

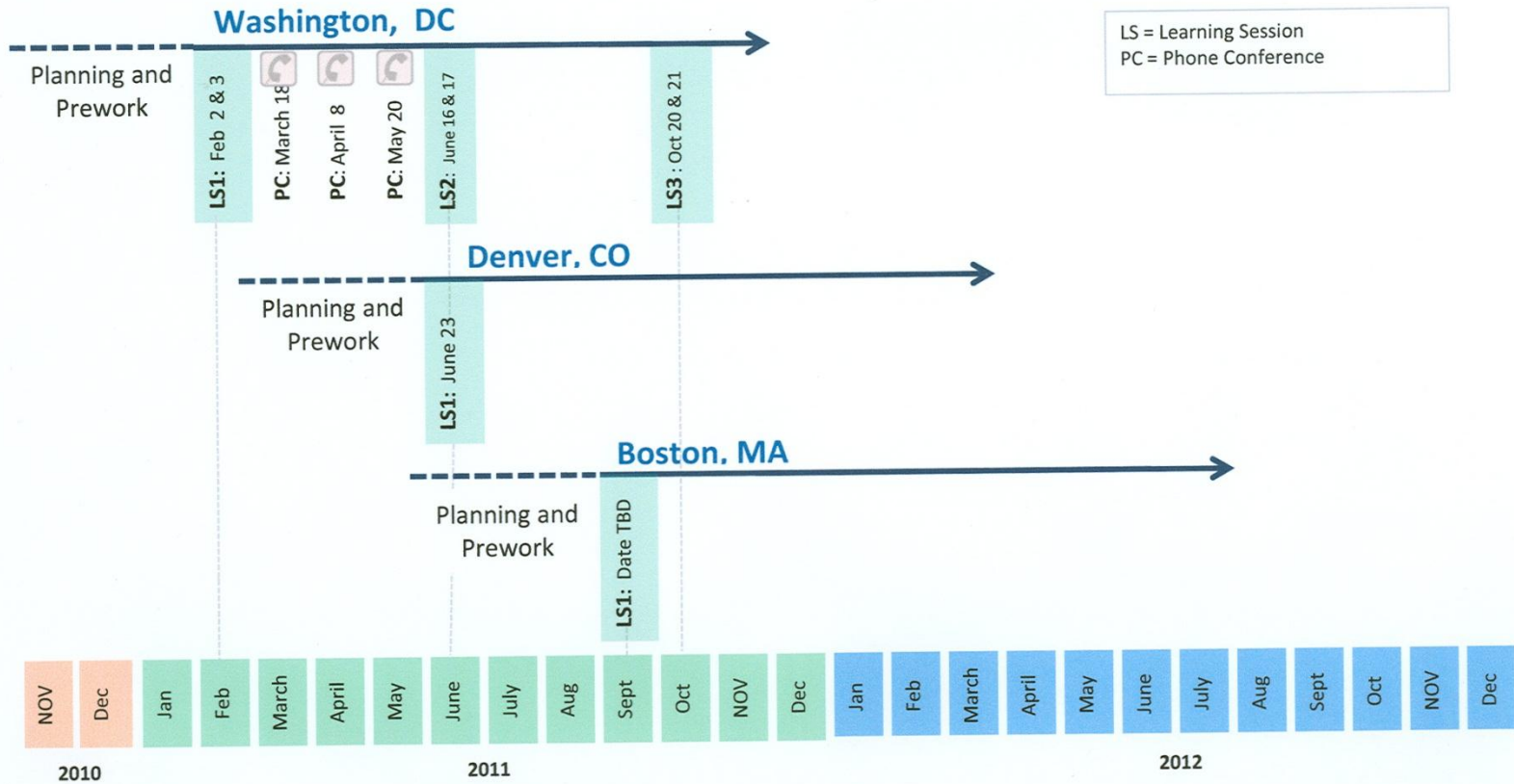
Got Transition? – Getting to “Yes”

The National Health Care Transition Center in July 2010

- Assuring **health care transition implementation** in health care practices as a result of quality improvement learning collaboratives
- Providing access to proven **health care transition tools** for professionals, youth, and families
- Helping state and national partners measure their progress and develop **health care transition policies and initiatives**
- Hosting conversations using social media technology as the “go to” resource for **health care transition information and networking**
- Promoting **policy changes** for better access to health care transition services including improved health care provider reimbursement



Got Transition HCT Learning Collaboratives Timeline



Center for Medical Home Improvement 4-26-2011

Six Core Elements for Health Care Transition (HCT) Improvement

Pediatric Health Care Setting	Adult Health Care Setting
<p>1 Transition Policy a) Develop a practice transition policy & share among providers, staff, youth, and families b) Educate all staff about HCT best practices</p>	<p>1 Privacy and Consent Policy a) Develop a practice privacy and consent policy & share among providers, staff, patients, and families b) Educate staff re: privacy & consent practices</p>
<p>2) Transitioning Youth - Registry Identify transitioning youth (current/future), enroll in a transition registry, monitor preparation, planning & outcomes (coordination)</p>	<p>2) Young Adult - Patient Registry Identify/enroll young adults in a practice registry, indicating levels of complexity; monitor adaptation to adult care model and health & wellness status</p>
<p>3) Transition Preparation Plan and use visits/other strategies to coordinate a developmentally appropriate, step-by-step, flexible transition process with youth/family; Assess and track youth readiness for adult care</p>	<p>3) Transition Preparation Share across practice mission and operational procedures; discuss adult model of health care and explain all practice access options (handout); Assess young adult personal responsibility and self-care abilities</p>
<p>4 Transition Planning a) <u>Visits</u>: Plan & hold HCT visit(s) with youth & family up to 4 years prior to care transfer; use a transition readiness assessment to evaluate knowledge, skills and plan needs. b) <u>Tools/Coordination of Care</u>: As part of the visit and beyond - use a transition action plan, a portable medical summary, and condition fact sheets (as needed) with youth, family, and team c) <u>Communication</u>: Notify adult primary care practice of each youth's pending transfer of care</p>	<p>4) Transition Planning For your pediatric practice colleagues – offer their transitioning youth a consultative “get acquainted & observation” encounter Request ahead of time / review - transition action plan, portable medical summary, and specific condition “fact” sheets (examples). Care coordinator assesses for/ addresses continuing patient needs/gaps & those of the practice; a list of relevant adult specialists matched to young adult needs is maintained and updated.</p>
<p>5) Transition & Transfer of Care Transfer from pediatric to adult care location: * In partnership w/youth & family, facilitate successful transfer of care to adult PCP/team using clear, direct communications (email, phone, in person “handshake”) and sharing of all comprehensive transition planning tools (e.g. transition action plan, portable medical summary with emergency plan (as needed) & condition fact sheets. *Assist primary & specialty transitions <i>separately</i> <u>Transition to adult model of care in same location</u> (see on right)</p>	<p>5) Transition/Transfer of care - All: Assess skills, proficiencies & insurance status <u>If Transfer from pediatric to new adult location:</u> Review transition documents & prepare for initial visit; talk with and receive communications from pediatric PCP/team (email, phone, in person “handshake”) Provide office visit/encounters for transitioning young adults; continue with and/or finish transition planning items sent/ assess self care proficiencies <u>If transition to adult model of care same location:</u> Identify PCP & a coordinator of care contact Assist with specialty care transfers</p>
<p>6) Transition Completion (Achieving) Pediatric PCP/team acts as a resource to adult patient & adult PCP/team following transfer. Contacts adult PCP/coordinators after ~3 months to ensure successful continuity of care. When evident, declare transition/transfer complete.</p>	<p>6) Transition Completion (Achieve/Declare) Consult with pediatric provider/team as needed; young adult is integrated within an adult care model; adult practice declares successful and complete HCT; continue forward in adult model of care and with appropriate care planning.</p>



SIX CORE ELEMENTS OF HCT IMPROVEMENT

1. Written policy – office or institutional policy
2. Registry – ability to anticipate and track
3. Preparation – readiness assessment and education
4. Planning – health care transition plan
5. Transfer
 - Adult model of care after age 18 for most youth
 - Proactive transfer of care to adult providers
6. Closure – defining the end of transition



HEALTH CARE TRANSITION IN YOUR PRACTICE

- Three key steps
 - **Preparation** – assuring that young adults are ready to manage their own health care as independently as possible
 - **Planning** – assuring that health care transition needs are anticipated and responsibility is clear about who will do what when (youth, parent, physician/provider)
 - **Implementation** – assuring the smooth and seamless transfer of care from pediatric to adult health care



PREPARATION

- Can a youth...?
 - Name their primary care physician
 - Name their insurance carrier
 - Make an appointment for an office visit
 - Refill a prescription
 - Name their allergies
 - Summarize their past medical history
 - Provide a family history
 - Respond to a personal health emergency (or that of someone else)



PREPARATION

- Can a youth with a chronic condition(s)...?
 - Do all of the above and...
 - Name his/her condition(s)
 - Name his/her specialty care physicians
 - Name his/her medications; side effects
 - Understand impact of condition on ability to function independently
 - Anticipate health-related needs in new settings (going to college, new job, military service, etc.)



PLANNING

- Transition plan initiated by age 14
 - May be basic at first
 - Refined at annual visits until transfer of care
 - More complex for children with special health care needs
 - May be a section of a written care plan
- Transition registry
 - Provides means of anticipating youth in the transition age group (14 to 22)
 - Provides means of tracking transition related activities
 - Provides means of evaluating transition performance



IMPLEMENTATION

- Creation of portable medical summary
- Creation or use of condition-specific “fact sheets”
- Availability as consultant for new adult provider
- Direct communication with new adult provider
 - Phone conversation
 - Agreement on timing of transfer
 - Transfer checklist
- Closure or completion of transition



HEALTH CARE TRANSITION CLINICAL REPORT

- Pediatrics, July 2011
- Developed by an expert authoring group
- Jointly authored by AAP, AAFP, and ACP
- Reviewed by large and diverse constituency

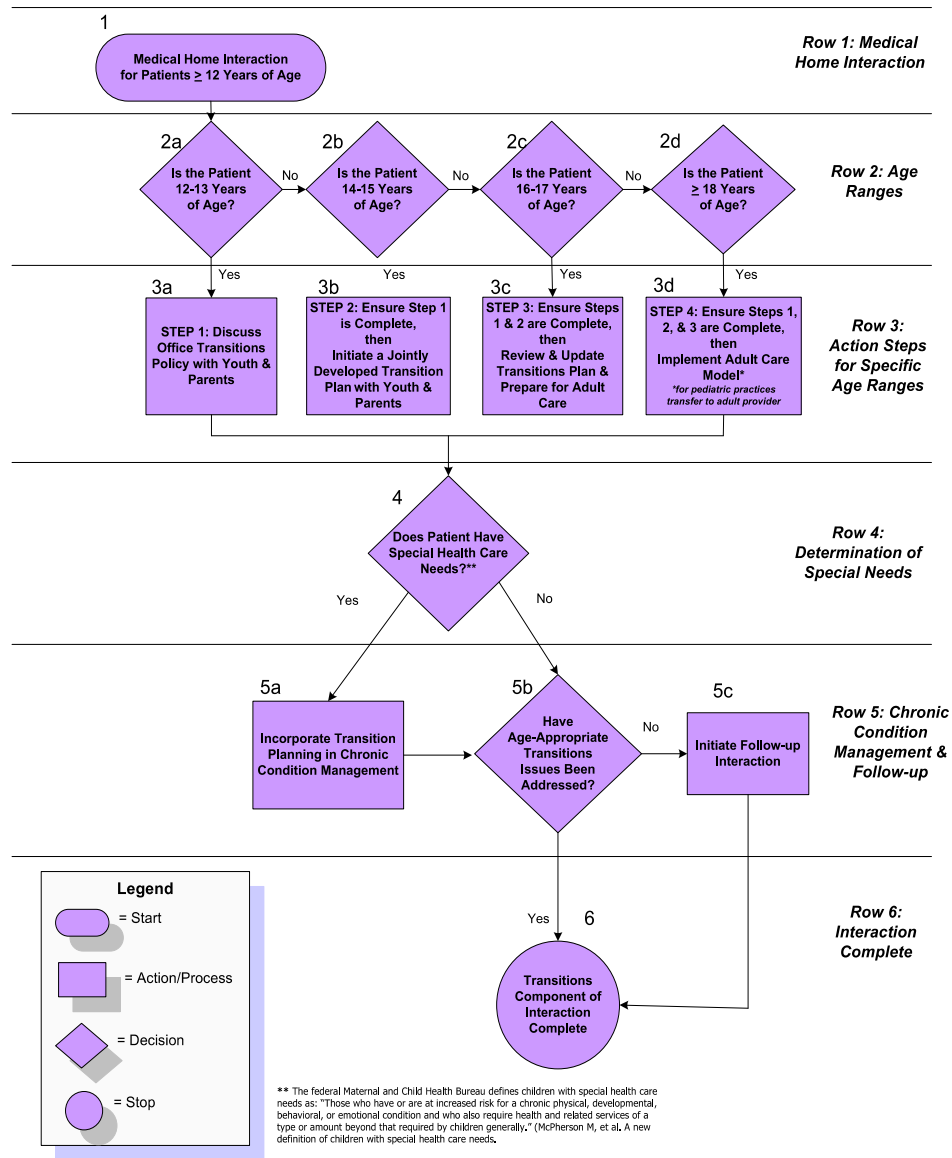


HEALTH CARE TRANSITION CLINICAL REPORT

- Targets all youth
- Algorithmic structure provides logical framework
 - Branching for youth with special health care needs
 - Framework for future condition or specialty specific applications
- Explicit guidance about practice structure and process beginning at the 12 year check-up
- Extends through the transfer of care to an adult medical home and adult specialists



Health Care Transition Planning Algorithm for All Youth and Young Adults Within a Medical Home Interaction



HEALTH CARE TRANSITION MILESTONES (FROM THE ALGORITHM)

- Age 12 - Youth and family aware of the practice's health care transition and transfer policy
- Age 14 – Health Care Transition plan initiated
- Age 16 – Youth and parental expectations and preferences regarding adult health care
- Age 18 – Transition to adult model of care
 - (if appropriate for cognitive ability)
- Age 18 – 22 – Transfer of care to adult medical home and specialists



RESOURCES

- www.gottransition.org
- www.hrtw.org
- <http://jaxhats.ufl.edu>
- www.mahec.net/quality/chat.aspx?a=10
- Join the National Health Care Transition Center on Facebook – search GotTransition

- cooley@cmf.org



REFERENCES

- AAP, AAFP, ACP: A Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs. *Pediatrics*, 2002, 110:6, 1304
- AAP, AAFP, ACP: Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*, July, 2011
- White, PH. Destination known: Planning the transition of youth with special health care needs to adult care. *Adolescent Health Update*, 2009, 21:3



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Health and Disability SIG

- Next Meeting: Tuesday, November 8th from 12:00-1:15 pm
- AUCD's Annual Meeting, Crystal City Virginia
- Contact sromelczyk@aucd.org or agriffen@aucd.org for questions or information about the SIG