National Health Care Transition Center

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www.GotTransition.org

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www.medicalhomeimprovement.org

- Got Transition is the National Health Care Transition Center made possible through a cooperative agreement with the United States Maternal and Child Health Bureau
- Got Transition is located at the Center for Medical Home Improvement at Crotched Mountain Foundation in Concord, NH

Plans for Today

1. Introduce topic of health care transition
   - Identify three data-based reasons why a focus on ***health care transition*** is so important to youth and families - today.
1. Align HCT efforts/needs with
   - FCC, the medical home, team-based care, care coordination, CYSHCN, and ACOs (our panel)
2. Highlight "The 6 Core Elements of HCT' & related tools
   - Strategies with Youth and Families
   - Examples
   - Measurement

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Health Care Transition Clinical Report
Transition of youth/emerging adults to an adult model of health care

- Optimal health care is achieved when each person, <u>at every age</u>, receives medically and developmentally appropriate care.

- The goal of a <u>planned health care transition</u> is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not

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Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home, Pediatrics, June 2011

Health Care Transition – What Does the Data Say?

500,000 youth with special health care needs are transitioning into the adult health care system each year

- **Parents:** Less than half (< 50%) get the transition support/ counseling they need (changing needs; insurance; care & action plans, etc.).
- **Youth:** Want help – finding a doctor, getting insurance, knowing what to do in an emergency, staying healthy
  - They worry about adult hospitalizations/familiarity
- **Clinicians** – (62 % pediatricians) transition supports need not start till age 18
  - Need new expertise

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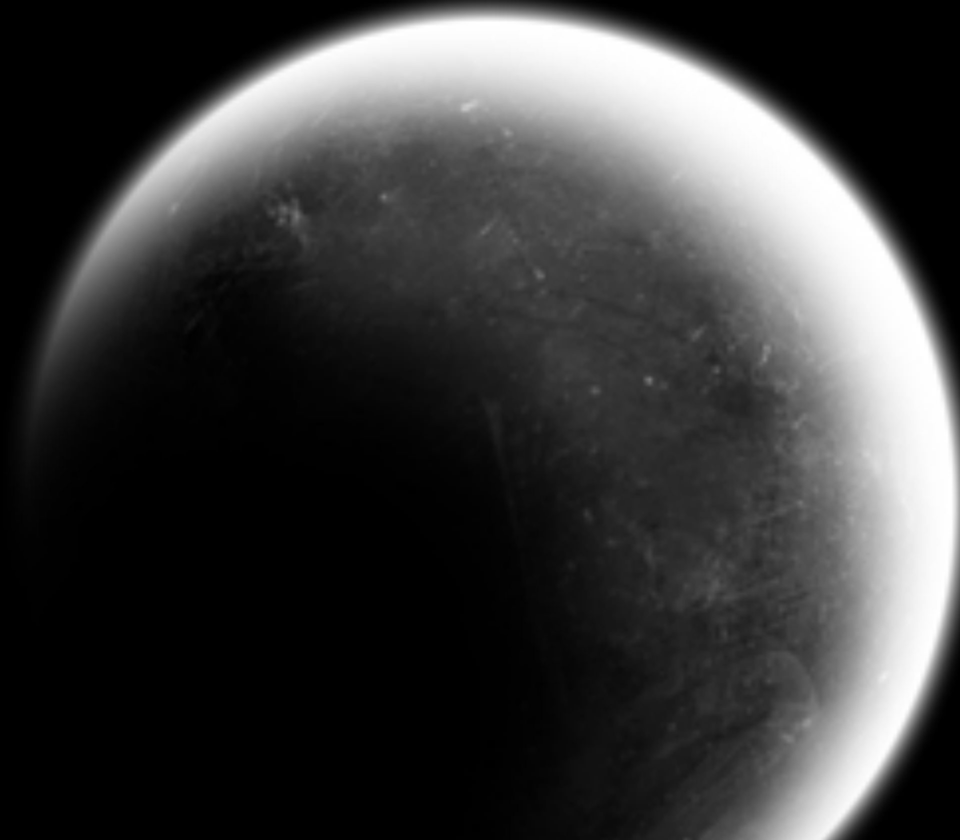
Those Adolescent Years, or *"The Dark Side of the Moon"*



<u>DID YOU</u> * Have/know a doctor *Understand insurance *Make own appointments * Fill prescriptions * Make healthy choices * Grasp anatomy/physiology * Listen to your elders?

The literature sounds similar for - Diabetes, Sickle Cell Disease, Autism, Juvenile Rheumatoid Arthritis, Seizure Disorders, Rare Metabolic Conditions, etc.

- Address topic: 9500 surveys youth/families with Diabetes
  - 50% discussed changing needs with specialist,
  - 30-42% of these talked about shifting to an adult clinician
- Adolescents worry about the unfamiliar, paying bills, being understood, treated as an individual
- Steps – early age; gradual continuous process; written supportive material & facilitated collaboration across pediatric and adult providers

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Recommended Health Care Strategies, Plus Youth/ Family Engagement Plus Protective Factors (especially for/during the dark side of the moon).

1) Medical Home
2) Core Knowledge & Skills
3) Portable Medical Summary
4) Health Care Transition Plan
5) Primary Preventive Care
6) Health Insurance

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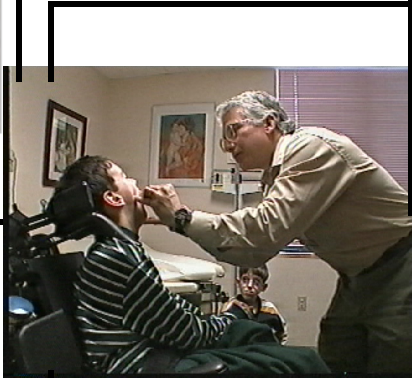
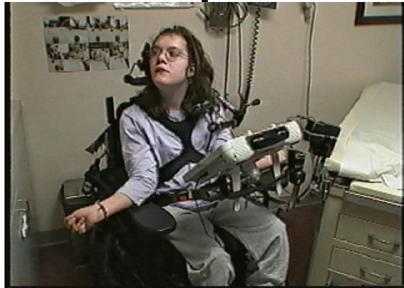
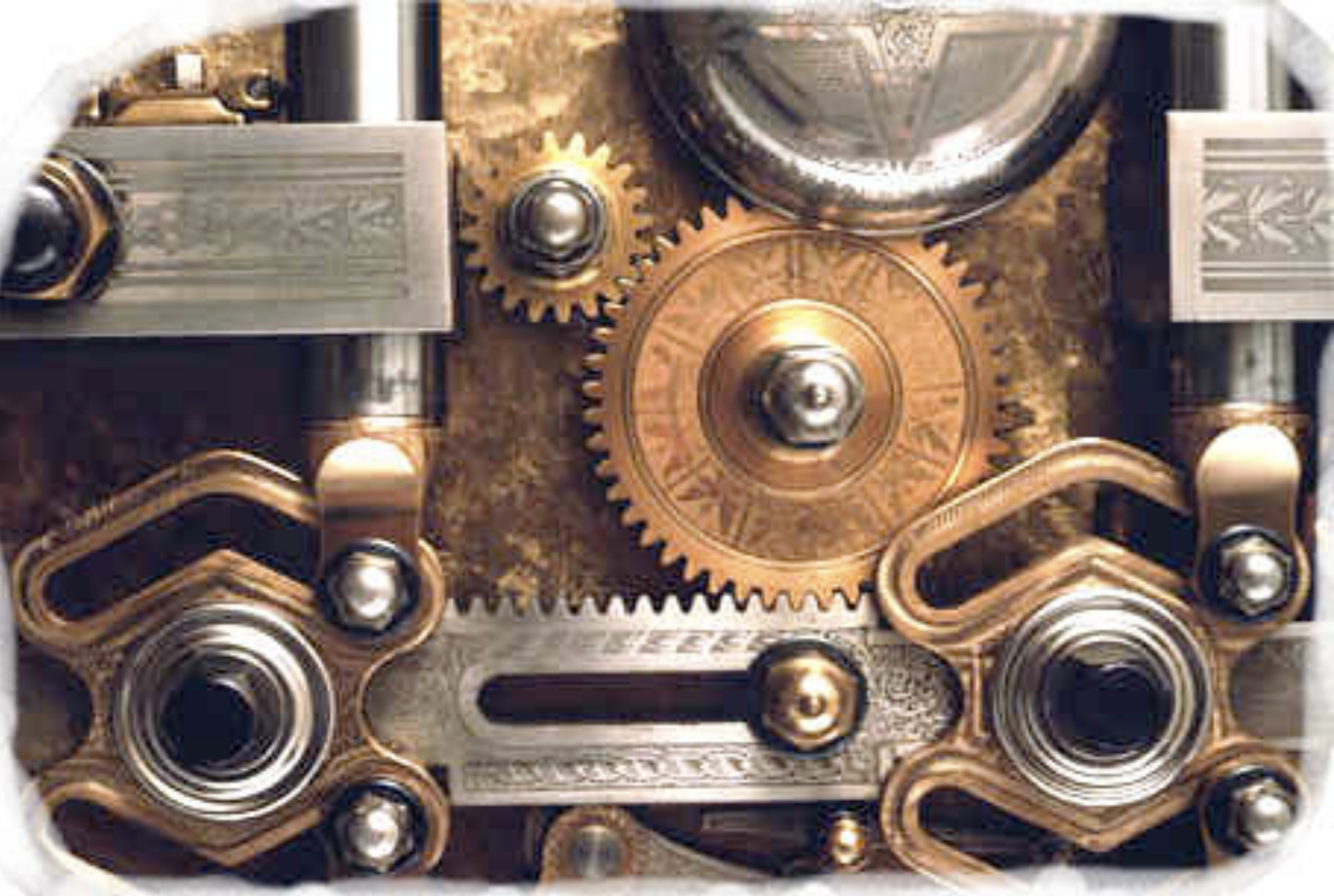
"Exceptional"
Coordinated
Medical Home





MEDICAL HOME: A LIVING, BREATHING, COMPLICATED & COMPLEX ENVIRONMENT



The Medical Home & Care Coordination (greases the wheels); " you can't have one without the other"

Health Care Transition Requires Relational Coordination

Coordinated Steps & Coordinated Activities:

Coordinated Steps	Coordinated Activities
① Preparation	✏ Early expectations (age 12), anticipatory guidance
② Planning	✏ Education, skills
③ Implementation	✏ Communication, follow up

A SIMPLE HEALTH CARE TRANSITION CHANGE PACKAGE

- Consensus exists regarding needed health care transition supports
- Recent AAP/AAFP/ACP clinical report
- Change package = road map and tools for improvement
- Manageable series of steps for practice settings

Six Core Elements of Health Care Transition

Pediatric Health Care Setting	Adult Health Care Setting
1) Transition Policy **-** policy	**1) Young Adult Privacy and Consent Policy**
2) Transitioning Youth Registry - Registry	**2) Young Adult Patient Registry**
3) Transition Preparation **-** Readiness assessment	**3) Transition Preparation**
4) Transition Planning - Action plan, portable medical summary & emergency plan	**4) Transition Planning**
5) Transition and Transfer of Care - HCT summary & transfer of care checklist	**5) Transition and Transfer of care**
6) Transition Completion **-** strategies	**6) Transition Completion**

H
C
T

Learning Collaboratives

Teach each other

Test & Vet New Ideas

Engage Youth

Listen to families

Set goals

Measure progress

Celebrate!

CORE ELEMENT #1
HEALTH CARE TRANSITION POLICY/APPROACH

- Policies - inform patients and staff
- Policies- provide consistent standards against which to measure performance
- Pediatric settings
  - Transition Policy/Approach
- Adult setting
  - Young Adult Approach
    - Privacy and Consent Policy

Core HCT Element #1: Pediatric Practice Example

Transition of Care Policy for Youth and Young Adults

"We at ____Pediatrics believe that a smooth transition from adolescence to young adulthood includes the clear and deliberate transition from a pediatric to an adult health care model. This process requires joint planning, preparation and actions beginning by age 14.

By age 19, all the youth in our practice will be prepared to transition to an adult model of care with modifications as needed for youth with intellectual disabilities.

We honor the preferences of the patient and family regarding the best time for transfers to an adult primary medical home, but generally expect this to occur sometime around age 18-20 years of age. We will make every effort to help coordinate this transfer of care to the patient's new medical home."

CORE ELEMENT #2
REGISTRY

- What are we trying to improve and for whom?
  - Identify, track, monitor transitioning youth and young adult patients
    - Pediatric – Transitioning Youth Registry
    - Adult – Young Adult Patient Registry

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CENTER FOR MEDICAL HOME IMPROVEMENT (CMHI) - GOT TRANSITION?
THE NATIONAL HEALTH CARE TRANSITION CENTER
REGISTRY SAMPLE FOR TRANSITIONING YOUTH
WITH/WITHOUT SPECIAL HEALTH CARE NEEDS

SIX CORE ELEMENTS FOR HEALTH CARE TRANSITION &/OR TRANSFER OF CARE

								Date:	Date:	Date:	Date:	Date:	Date:	Date:	Date:
DOB	Calc Age	NAME	Primary Diagnosis / ICD9 Code	Serverity/ Complexity (See below)	Insurance status	Date Last Seen	Next Sheduled Appointment	1. Transition Policy Shared	2.Date youth entered into registry	3. Preparation Readiness Assessment	4. Planning - summary, action, & emerg plan	5a. Transfer of Care/Inform. Package Assembled /Sent	5b. (Or) Transition to clear adult model of care	6. Transition Completion & Evaluation	Other?
3/4/95	15.3	Mary Smith	seizure disorder	3					yes						
9/2/96	14.8	Billy Jones	asthma	1					yes						
12/25/97	13.5	Susan Cue	congenital heart disea	1					yes						
1/17/93	17.6	Thomas Train	JRA	2					yes						

Complexity Scoring Example
Low to high complexity
3= High Complexity
2= Moderate Complexity
1= Low Complexity
{Based upon level of need and system use, on organ invovlment, medications, treatments equipment, socioeconomic concerns, etc}

Enrolling Youth/ YSHCN into a Health Care Transition Registry

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CORE ELEMENT #3
TRANSITION PREPARATION

- Transition Readiness Assessment
  - Assess and respond to readiness for adult health care
- Pediatric
  - Begin by age 14
  - Repeatedly address gaps in knowledge and skills
- Adult
  - Continue to track Transition Readiness Assessment
  - Orient young adult to adult model of care and to adult practice

TRANSITION PLANNING- Readiness

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)

Readiness Assessment

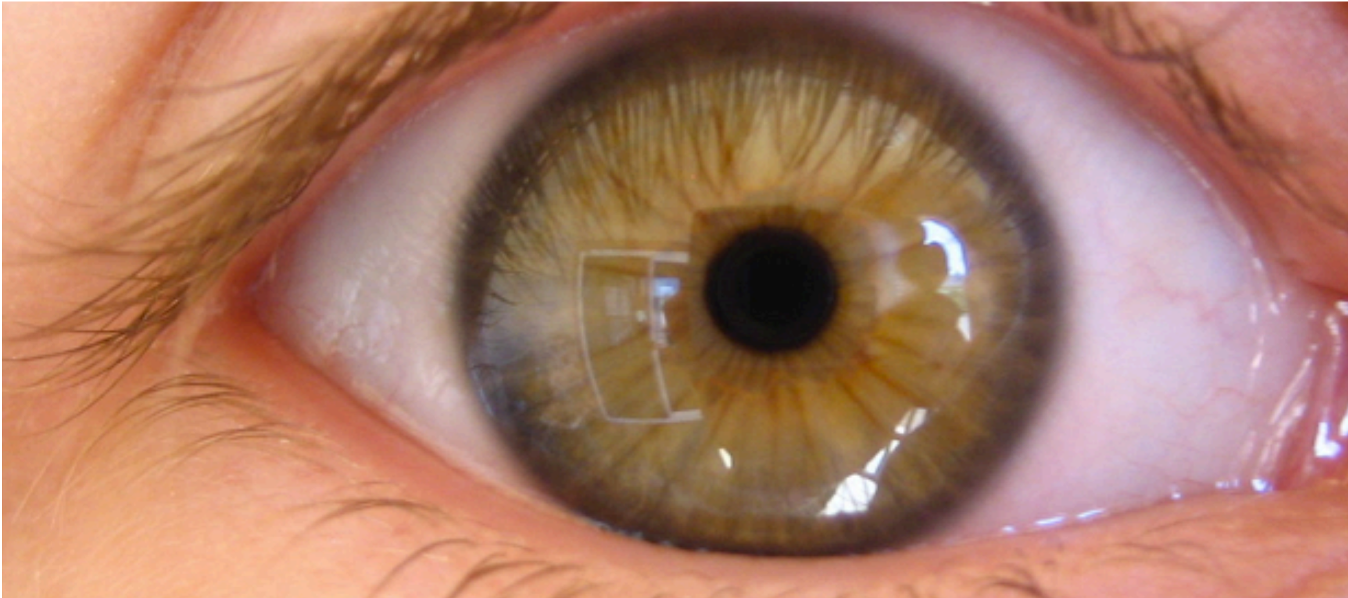
GotTransition? Health Care Transitions (HCT) and Changing Roles for Youth

Transition Readiness Assessment

NA – if non applicable

Health & Wellness 101 The Basics:	Yes I do this	I want to do this	I need To learn	Someone else will have to do this - *Who?* /NA
1. I understand my health care needs and or disability				
2. I can explain my needs to others.				
3. I can explain to others how our family's customs/beliefs might affect health care decisions and/or treatments.				
4. I carry my health insurance card everyday				
5. I know and pay attention to my health and wellness baseline (pulse, respiration rate, elimination habits)				
6. I make and track my own appointments				

Readiness Assessment / Anticipatory Guidance



CORE ELEMENT #4
TRANSITION PLANNING

- Basic **care planning** tools
  - Health Care Transition Action Plan started by age 14
  - Portable Medical Summary
  - Emergency Care Plan (if needed)

- Identify adult primary and specialty care settings
- **Pediatric and adult settings –
  - Continue to address needs and set transition goals with youth/young adult and family

Health Care Transition Action Plan

Health Care Transition (HCT) Action Plan

Youth/Young Adult: **DOB** Pick DOB **Family/Guardian:**

Primary Diagnosis: **Other Diagnosis:**

Date of 1st Action Plan: Pick Date of 1st plan **Update to Plan:** Update date Update date Update date Update date Update date Update date

HCT PLANNING		Related Health/Wellness Information (labs, etc.)	Plans/Intervention	Team Member Responsible
Youth/family Priorities, concerns, goals				
Clinician Priorities, concerns, goals				

KNOWLEDGE OF HEALTH ISSUES/DIAGNOSIS	X	Notes:	Plans	Team Member/When
1. Understands his/her health care needs, and disability and can explain these needs to others.	☐			
2. Can explain to others how our family's customs and beliefs might affect health care decisions and medical treatments.	☐			
3. Knows his/her health and wellness baseline (pulse, respiration rate, elimination habits).	☐			
4. Knows health symptoms that need quick medical attention.	☐			
5. Knows what to do in case he/she have a medical emergency.	☐			

Matches each item in the readiness assessment tool.

Got Transition – the National Health Care Transition Center is funded through a cooperative agreement (U39MC18176) from the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of

CORE ELEMENT #5
TRANSITION AND TRANSFER OF CARE

- All 18 year olds transition to adult model of care
  - Regardless of setting – pediatric or adult
  - Modifications with guardianship arrangements
- Explicit, direct communication between pediatric and adult settings before and after transfer of care
- Use Transfer of Care checklist
- Develop "transition package" of needed information

GOING WELL? GOING NOT SO WELL? DEBRIEF ACROSS TEAMS

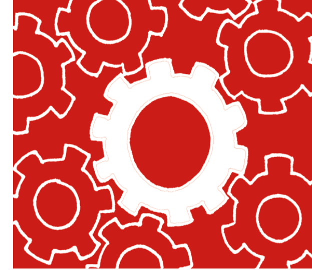
RELATIONAL COORDINATION (J. GITTELL)

Interventions to enhance -

1. Shared Goals
2. Frequent and timely communication
   - Across silos and organizations
3. Mutual Respect

CORE ELEMENT #6
TRANSITION COMPLETION

- Plan for on-going communication/consultation between adult and pediatric teams until transition is complete
- Agreement among pediatric and adult providers and young adult (and family) when transition is complete
- Follow up / Loop closed?



Coordinated Care

Assessment

Goal setting/ planning

Care Plan/ Planning

Care Plan Use & Actions

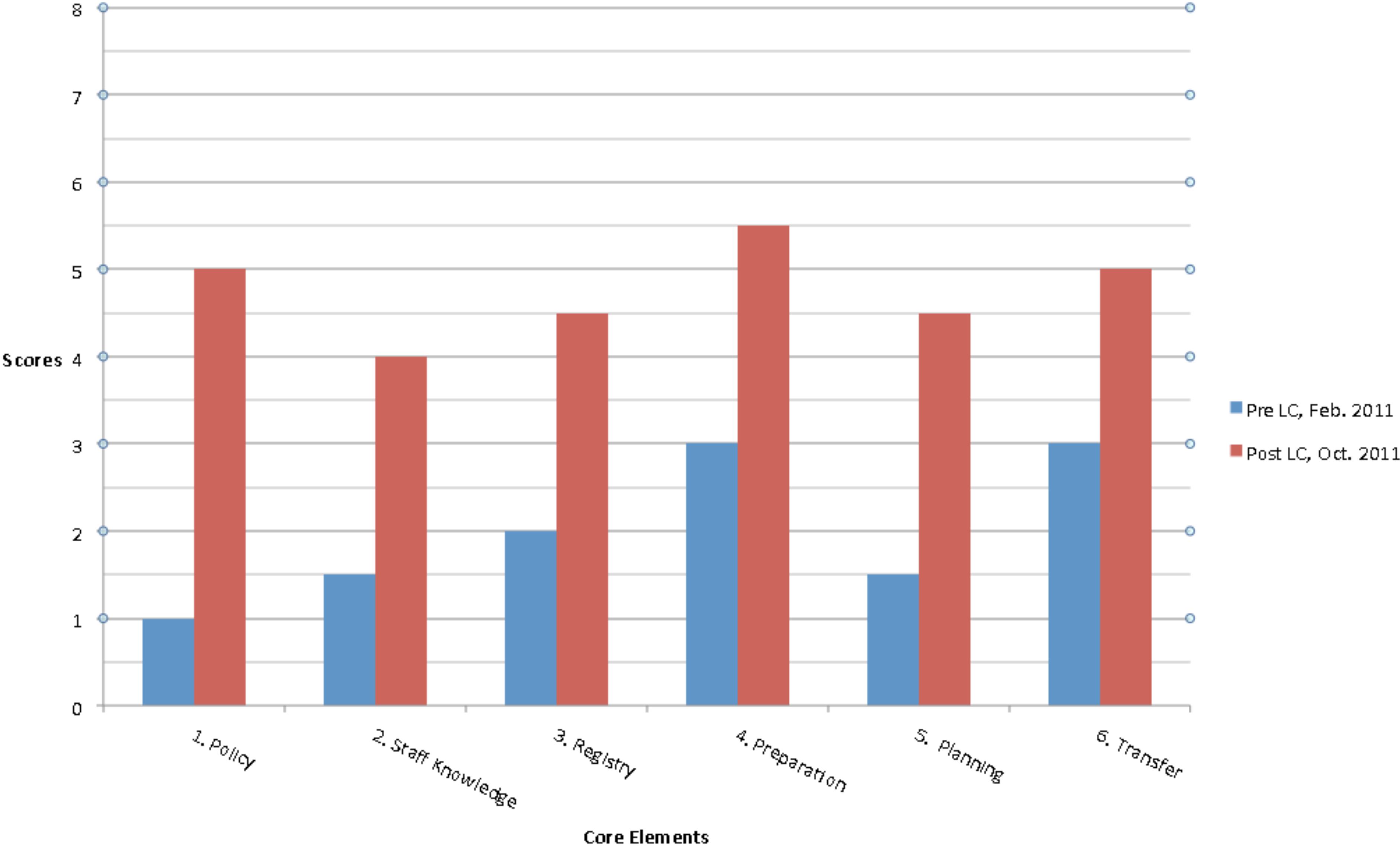
Monitoring/ updating

Delivery of Patient & Family-Centered Care Coordination Services

MEASURING HEALTH CARE TRANSITION IMPLEMENTATION

- Health Care Transition Index
  - Quality improvement tool modeled after Medical Home Index
    - Self-assessment
    - Numerical scores
    - Six indicators
    - Pediatric and adult versions
    - Each indicator has achievement Levels 1 – 4
      - Basic to most comprehensive transition support
      - Each level can be judged partially or fully implemented

HEALTH CARE TRANSITION INDEX RESULTS
Pre and Post HCT Learning Collaborative



Getting from basic to great HCT Support

Basic Visit

- 15 minute check up
- Rotating team
- Follow wellness protocol
- What can we do for you today?
- Reactive response
- Drift apart

Great Visit

- What would be even better?

Getting from basic to great HCT Support

Basic Visit	Great Visit
• 15 minute check up	• *This is how we approach HCT (expectations)"*
• Rotating team	• *We know you - long-term; we prepare for your visits (proactive planned care)*
• Follow wellness protocol	• *Continually & together we use readiness assessment, building gradually with renewed **care/action plan** steps (care coordination)*
• What can we do for you today?	• *Help with clear steps (toward transfer to adult model of care (coordinated teamwork)*
• Reactive response	
• Drift apart	• *Follow up / check on success(!)*

QUESTIONS OR COMMENTS?

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OPENING DOORS TO A HEALTHY FUTURE