Opening Doors to a Healthy Future for Youth and Young Adults with (and without) Special Health Care Needs

W. Carl Cooley, NHCTC Co-Director
Jeanne W. McAllister, NHCTC Co-Director
Eileen Forlenza, NHCTC Cabinet Member
Mallory Cyr, NHCTC National Youth Program Manager

Purpose of Session

Participants will:

1) Be familiar with Got Transition? as a resource for youth, families, and state level transition initiatives
2) Understand and reflect upon the emotional dichotomy of applying for adult services based on stringent eligibility requirements
3) Explore best ideas and strategies to prepare young people, families, and health care teams to successfully navigate transition process steps and transfers of care

Why This? Why Now?

- **Less than half** of US youth with special health care needs get the **transition support** they need
- Positive transitions begin with **prepared youth and families**
- For **planned and successful health care transitions,** pediatricians and adult primary care providers need tools and concrete methods to address barriers and improve care

Help is on the way…

- New Health Care Transition professional practice standards (AAP, ACP, and AAFP)
- National health care reform efforts affecting youth and young adults
- Health care transition remains one of six performance priorities for national maternal and child health policy
- Got Transition – new National Health Care Transition Center (www.gottransition.org)

The New American Academy of Pediatrics Health Care Transition Agenda

2007 - Improving health care transitions for youth is a "top ten" AAP priority

2008 - National survey of AAP members on health care transition issues revealed the need for more information and support

2008 - AAP commissioned a review of health care transition practices, models, and evidence base

2008 – AAP Transition Advisory Meeting crafted a four part agenda:

1. Publish new new clinical report on best practices in health care transition
2. Promote improved reimbursement and financing for HCT
3. Develop training and medical education resources
4. Advance health care transition research

Health Care Transition Clinical Report – 2010-2011

- Serve as basis for the four AAP HCT agenda items (best practice, financing, education, research)
- Developed by an expert authoring group including youth and families
- Jointly endorsed by AAP, AAFP, and ACP
- Reviewed by a large and diverse constituency
- Planned publication in Pediatrics in Spring 2011
- Planned simultaneous commentary in AAFP and ACP journals

Health Care Transition Clinical Report

- Targets all youth
- Provides algorithm-based logical framework for HCT in health care office settings
  - Branches for youth with special health care needs
  - Provides framework for future condition or specialty specific applications
- Outlines concrete elements of 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 Milestones
(from the algorithm)

- Age 12 - Youth and family aware of 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 identified
- Age 18 – Transition to adult model of care in all settings
  - (as appropriate for intellectual ability)
- Age 18 – 22 – Transfer of care when necessary to adult medical home and adult specialists

Health Care Transition in Primary Care Practice

Three primary elements

Preparation – assuring that young adults are ready to manage their own health care as independently as possible; families are ready to support this

Planning – assuring that health care transition needs are anticipated; responsibility is clear about who will do what and when (youth, parent, physicians/providers)

Implementation – assuring the smooth and seamless transition and transfer from pediatric to adult (model of) health care

NHCTC Goals

1. Surveillance/needs assessment

1. Evidenced Based Practice & Innovative Strategies
   - Learning collaboratives

2. Youth/Family Leadership/Learning Communities

3. Policy Supports (financial/non-financial)

4. Information Exchange and Dissemination

State Title V Transition Programs
Efforts and Innovations

Review of National Survey results* and Title V block grant narrative applications with follow-up queries of state Title V CSHCN directors

- Identifying Innovative approaches
- Build evidence-informed practice
- Facilitate cross-state partnerships
- Target needed areas of assistance

*initial GotTransition analysis of National Survey Health Care Transition results available on line at www.gottransition.org

Health Care Transition for All Youth (with and without special health care needs)

Why this? Why now?

- Transition ranks **lowest** among MCHB core outcomes
- **Less than half** of US youth with special health care needs get the transition support they need
- Only **13%** of primary care practices in a Rhode Island study had a written office policy regarding the transition and transfer of youth from pediatric to adult care
- In a 2010 study**, 50%** of internists and **62%** of pediatricians believed finding an adult medical home for young adults with chronic conditions to be difficult

Why this (HCT), Why Now?
Youth & Families (Surveys: NYLN & HRTW-MN)

- **Families say there is a lack of specified health care transition information/support.**
  - -Are families wants and needs the same as their youth?
  - -Awareness of intergenerational tension among families and youth

- **What do *youth* say they want to know**
  - -What to do in an emergency? (health, environmental, terrorist attack)
  - -How to find an adult doctor?
  - -What's the plan if I get worse?

- **Navigating the System** (families, youth/young adults):
  - -Solo, guided support and guides
  - -Increased essential knowledge learned over time
  - -Level of assistance needed may change for various reasons

Why this? Why now?
Practices/Professionals

Practices/professionals (often) do not have:

- HCT policies (privacy and consent policies)
- A package of reliable HC/HCT information
- Education/preparation re: HCT care processes
- Clarity of roles around transfer of care
- Care coordination capability
  (for transition & transfer of care)

Pulling threads of this tapestry together; together
Why is it important to focus on health care transition-now?

Buzz 2" with neighbor; craft/share 1 response each

Share with all: 1 word or 1 phrase that reflects your answer.

Health Care Transition Learning Collaboratives
Partners in Transition *Transformation*

- Washington DC HCT Learning Collaborative
  First learning session – February 2 and 3
- Denver HCT Learning Collaborative
- Boston HCT Learning Collaborative

Health Care Transition Learning Collaboratives (LC)

- Charter – Overview
  - Aim, Goals, and Measures
- HCT Index – Measure of current practice
  - Pediatric < 18
  - Young Adult > Age 18
- Planning Guide for LC Leaders
  - Six Core Elements & Package of Supports
- Break through Series Learning Collaborative
- Additional Measurement & Evaluation Strategies

Model for Improvement

What are we trying to accomplish?

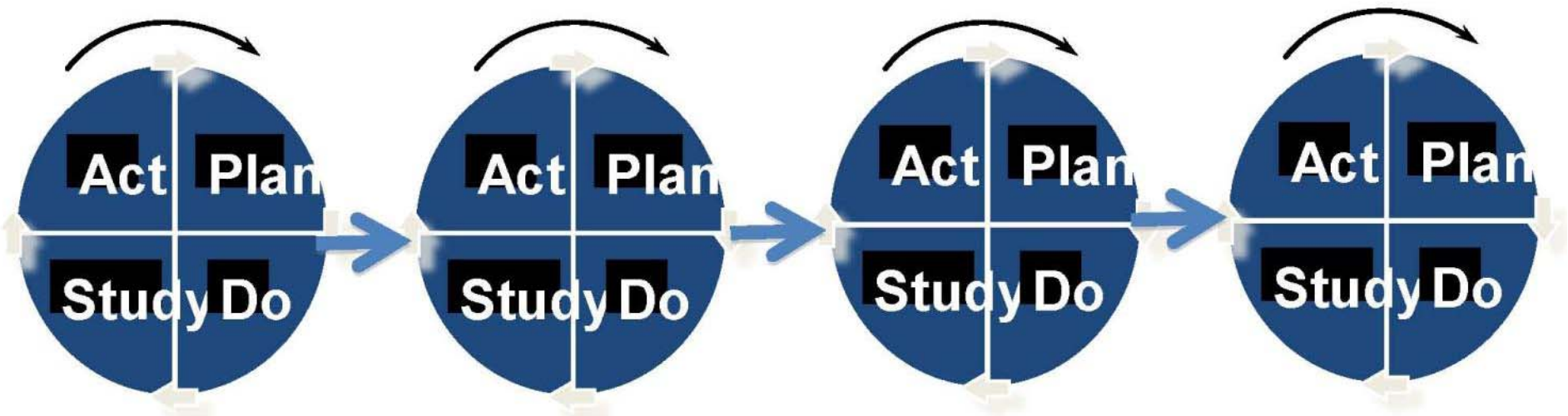
Prepared Planned Successful HCTs

How will we know that a change is an improvement?

HCT Indices & Measure Set

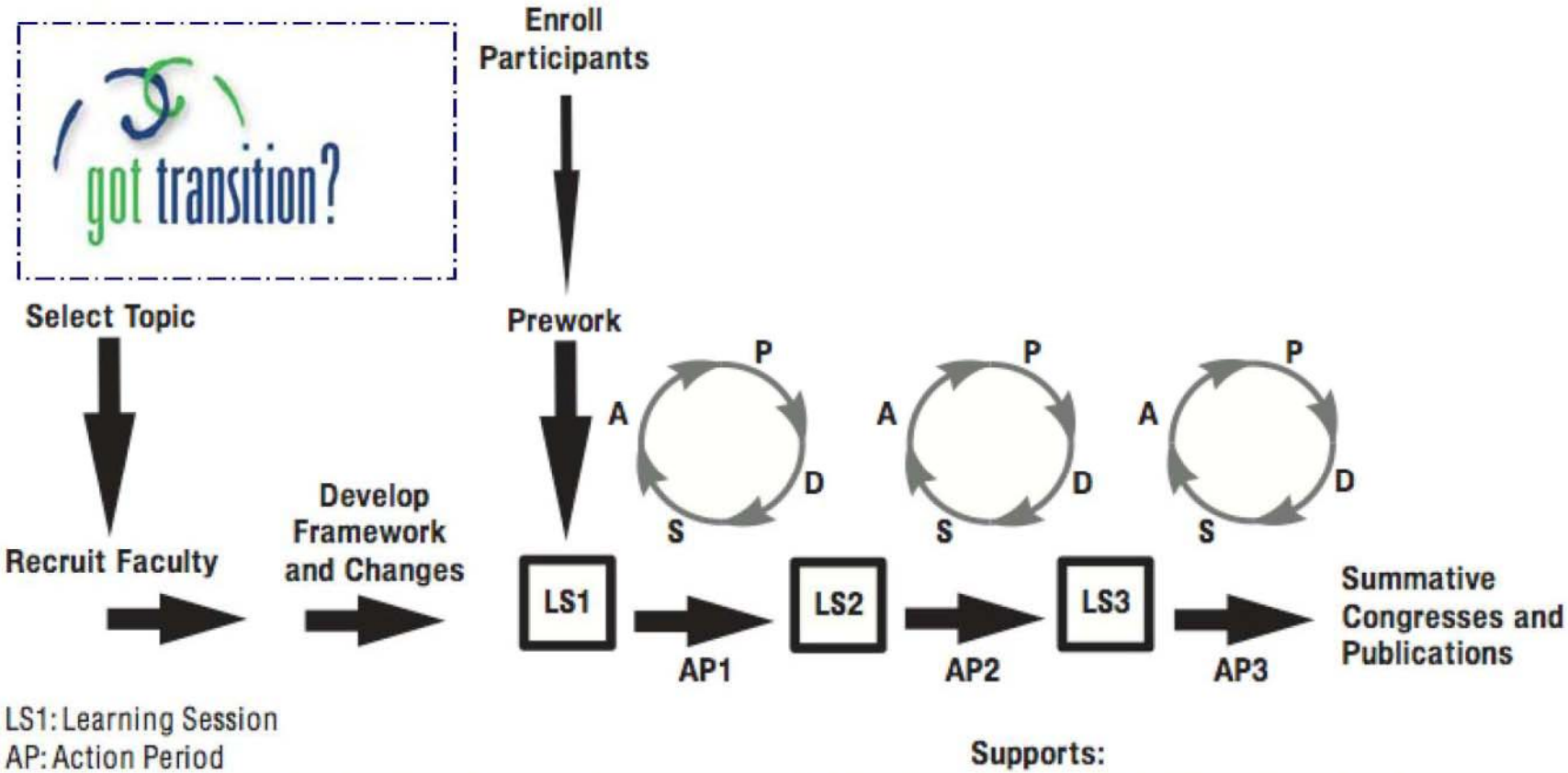
What change can we make that will result in improvement?

Six Core Elements



Rationale → Core Elements → Learning Community → *Tests* of Change →

Knowledge → Skills → Proficiencies



Learning Sessions: Structured face time **AP Supports**: Webinars, website, registry, data help, etc.

Core Element - * Policy * Registry *Preparation, *Planning, *Transfer of Care * Completion

Test – Learn – Implement – Measure – Spread

Pediatric Health Care Setting	Adult Health Care Setting
1 Transition Policy	**1 Privacy and Consent Policy**
2) Transitioning Youth – Registry	**2) Young Adult - Patient Registry**
3) Transition Preparation Transition process	**3) Transition Preparation** Adult model of health care
4 Transition Planning a) Transition readiness assessment to b) Tools/Coordination of Care: transition action plan, a portable medical summary, and condition fact sheets c) Communication:	**4) Transition Planning** a) Consultative "get acquainted encounter b) Transition action plan, portable medical summary, and specific condition "**fact**" sheets (examples). c) Care coordination
5) Transition & Transfer of Care Transfer from pediatric to adult care location: communications (email, phone, in person "handshake") *and* sharing of all comprehensive transition planning tools *Assist primary & specialty transitions *separately*	**5) Transition/Transfer of care -** All: Assess skills, proficiencies & insurance status Review transition documents /communications PCP & a coordinator of care contact Assist with specialty care transfers
6) Transition Completion *(Achieving*) When evident, declare transition/transfer complete.	**6) Transition Completion *(Achieve/Declare*)** Young adult is successfully integrated within an adult care model

6 Core Elements of HCT Improvement in Primary Care Practice:

- HCT Policy
- Registry
- Preparation (process)
- HCT Action Plan
- Transfer of Care
- Follow up/completion

Public Health & Primary Care

- Outreach/Partnerships
- &
- Family Engagement
- Care Coordination

Real People, Real Stories, Real Impact

Strength Based Language vs. Deficit Based Language

- What is the difference?
- Why does it matter?
- We want to get you **thinking** and **feeling**…
  - -Interactive activity
  - -What was that like?
  - -What supports are needed for both?

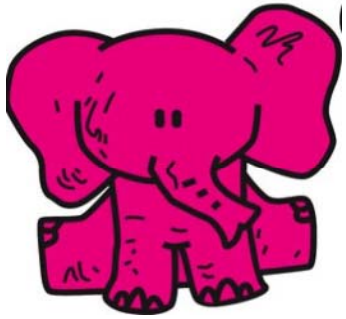
Our stories:

- The “eligibility interviews” of Spring/Summer 2010
- Big step in real life transition for a young adult learning to navigate the system
- Case worker- capacity & skill set

got transition?

The emotional toll it takes:

- The cycle continues
- Grief cycle is activated
- Makes planning difficult



Leads to Secondary Conditions:

- Depression
- Substance Abuse
- Anxiety
- Dis-Empowerment
- Anger- as a result of deficit based focus

Top 5 Strategies for Parents to Support Youth for a Successful Health Transition

1. Expose your youth early in the process to the reasons behind strength-based vs. deficit-based language and how it impacts them.

2. Embrace the difference between health and health-care and understand your role in both.

3. Be proactive in seeking guidance about whom you should add to your child's medical home team – think about who, why and when.

4. Critical information, including insurance card, health diagnoses, medications and treatment guidance should always be accessible to the youth – noted in their Blackberry, backpack, IPad, etc.

5. Establish a partnership with health care providers, grounded in trust and respect.

Top 5 Strategies for Youth to be Advocates in Transition:

1. Know your condition, be a teacher, and have **confidence** that you are the expert in your life.

2. Swallow your pride- Know when to ask for and accept help

3. Accept the support of your parents/providers to learn ways to take responsibility yourself

4. Broaden circle of support. Make others comfortable vs. fear of the unknown

5. Think outside the box, don't let your condition control your life. **Diagnosed but not defined**

Mallory Cyr, BFA
National Youth Program Manager
mallorycyr@yahoo.com

Eileen Forlenza
Cabinet Member
Denver, CO
Eileen.Forlenza@dphe.state.co.us

W. Carl Cooley, MD
NHCTC Co-Director & Medical Director
Center for Medical Home Improvement

Jeanne W. McAllister, BSN, MS, MHA
NHCTC Co-Director & Director
Center for Medical Home Improvement

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