Improving Health Care Transitions from Pediatric to Adult Care – Implementing the Six Core Elements of Health Care Transition

Tennessee Transition Summit
Tennessee Chapter AAP, Tennessee Pediatric Society Foundation, and Tennessee Department of Health
Nashville, TN
April 24, 2015

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Disclosure

“I have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider(s) of commercial services discussed in this CME activity.”
“First they make you button your own shirt, then they make you tie your own shoes...you gotta ask yourself — where's this all heading?”
Presentation Overview

1) The case for improving transitions from pediatric to adult care
2) 2011 Clinical Report on Health Care Transition and resulting Six Core Elements
3) Quality improvement strategy and transition learning collaborative results
4) Next steps...
Health Care Transition Overview

• Every year 500,000+ American youth with special health care needs leave the pediatric health care system and “graduate” into the adult system

• Some are able to independently negotiate their way into and around the adult health care system...

• But many need different levels of support as they navigate the chasm between pediatric and adult health care
US National Survey of Children with Special Health Care Needs

- Every five years the US Maternal and Child Health Bureau conducts a national telephone survey of families about child health
- A subset of about 17,000 families have children with special health care needs
- The results from this subset inform progress on the US MCHB core outcomes
## Transition Core Outcome Performance

Transition is the US Maternal and Child Health Bureau core outcome with the lowest achievement nationally.

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>79%</td>
<td>screened early and continuously for special needs</td>
</tr>
<tr>
<td>70%</td>
<td>partner in shared decision-making</td>
</tr>
<tr>
<td>65%</td>
<td>can easily access community-based services</td>
</tr>
<tr>
<td>61%</td>
<td>have consistent and adequate insurance coverage</td>
</tr>
<tr>
<td>43%</td>
<td>receive coordinated, ongoing comprehensive care with in a medical home</td>
</tr>
<tr>
<td>40%</td>
<td>receive services needed to make appropriate transitions to adult health care, work, and independence</td>
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• BUT: If excluding follow-up questions about whether a discussion on a particular transition topic would have been helpful, a much smaller proportion of CSHCN have successfully met the transition outcome: **13%**
Transition Core Outcome Performance

• Youth with Special Health Care Needs that are least likely to meet transition core element:
  – Males
  – Those not speaking English in the home
  – With family incomes below 400% of poverty
  – With emotional, behavioral, or developmental conditions
  – With conditions that impact daily activities
  – Without medical home
  – Without insurance
Reasons for Low Performance:
Survey Results

• Youth/Families:
  – Inexperience assuming responsibility for health care decisions
  – Reticence leaving pediatric providers
  – Difficulty identifying adult providers
  – Fear of not knowing what to expect with new provider
  – Lack of insurance continuity
Reasons for Low Performance: Survey Results

- **Pediatric MDs:**
  - Lack of available adult doctors
  - Lack of payment for transition services
  - Difficulty in ending long-standing relationships
  - Lack of skills in transition planning including value of early start
  - Lack of knowledge about community resources
AAP Periodic Survey #71 2008 Results*

- 47% Assist with a referral to family or internal medicine
- 32% Assist with finding a primary care physician
- 45% Refer to adult specialists
- 33% Discuss consent/confidentially prior to age 18

* For all or most of their adolescents
Reasons for Low Performance: Survey Results

- Family Medicine/Internal Medicine MDs:
  - New young adult patients arrive without medical records
    - And with limited understanding of their health history and condition
    - And of navigating adult-centered care
  - Lack of payment for transition services
  - Insufficient communication with pediatric providers
  - Limited knowledge of childhood-onset chronic conditions
  - Lack of understanding that the youth’s life course transition is still in progress
### Internal medicine nephrologists (N=35)

<table>
<thead>
<tr>
<th>Survey Components</th>
<th>Percentages</th>
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<tbody>
<tr>
<td>Transitioned patients came with an introduction</td>
<td>75%</td>
</tr>
<tr>
<td>Transitioned patients know their meds</td>
<td>45%</td>
</tr>
<tr>
<td>Transitioned patients know their disease</td>
<td>30%</td>
</tr>
<tr>
<td>Transitioned patients ask questions</td>
<td>20%</td>
</tr>
<tr>
<td>Parents of transitioned patients ask questions</td>
<td>69%</td>
</tr>
<tr>
<td>Transitioned adults believed they had a difficult transition</td>
<td>40%</td>
</tr>
</tbody>
</table>

Maria Ferris, MD, PhD, MPH, UNC Kidney Center 2006
Survey of NH Adult Primary Care Providers

- Family physicians and internists
- 46% rarely/never received transition summary or call from pediatric PCP
- Barriers:
  - Time; reimbursement
  - Inadequate specialist support
- Comfort level:
  - More - asthma, hypertension, mental health, diabetes
  - Less - CF, metabolic disorders, autism, technology dependent
- What would help:
  - 95% written summary and support from specialists
  - 91% want to speak with pediatric provider
  - 84% written educational information about condition
More Reasons

• Majority of existing transition programs are tertiary-based often in specialty clinics or limited to subset of youth with complex needs, often starting the HCT process late in adolescence
• Little evidence characterizing effective transition interventions
• No consensus on transition outcome measures
• Majority of pediatric and adult care providers in separate systems and with limited clinical interaction
• Limited wide-spread awareness of the problem of pediatric to adult care transitions
Are there health outcomes associated with the health care transition process?
• Sickle Cell Disease in the 15 years...
  – Dramatic increases in survival and reductions in morbidity up to age 18

BUT...

  – Increased re-hospitalization rates from 18 to 35 years

  – Increased mortality for those over age 18 years
    • Often within 1 – 2 years of transition to adult care
• HIV

– Psychosocial challenges with transition to adult care
– Declining adherence to therapeutic regimen
– Decline in CD4 levels
• Childhood cancers
  – Past decade
    • Increased incidence of childhood cancer
    • Dramatic improvements in survival
  – More survivors reaching adulthood (1/640 adults)
  – Many survive with long term health issues or risks
    • Higher mortality, health complications, mental health issues

But...
  – less than 50% of adult survivors have had any cancer-related follow-up in previous two years
Perception of Transition Process

Pediatric Care → Faith, Trust, and Pixie Dust → Adult Care
Help is on the way....

- Health Care Transition Clinical Report
- Got Transition – www.gottransition.org
  – Formerly, National Health Care Transition Center
  – Now, Center for Health Care Transition Improvement
HOW TO GROW UP
Health Care Transition Clinical Report

• In 2011, Clinical Report on Health Care Transition published jointly by AAP/AAFP/ACP
  – Provides practice-based guidance (including step-by-step algorithm) on how to plan and implement better health care transition for youth
  – Integrates transition planning into medical home and ongoing chronic care management

• “Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home” *(Pediatrics, July 2011)*
Health Care Transition Clinical Report

• Targets all youth, beginning at age 12, and links the process to the medical home

• Algorithmic structure provides logical framework
  – Branching for youth with special health care needs
  – Application for primary and specialty practices serving children and young adults with variety of conditions
  – Structure for training, continuing education, and research

• Extends through the transfer of care to adult medical home and adult specialists

• Provides explicit template for planning, decision making, and documentation processes
Pediatric Health Care Transition Milestones
(from algorithm in Clinical Report)

- **Age 12** – Youth and family aware of practices health care transition and transfer policy
- **Age 14** – Health care transition planning initiated
- **Age 16** – Discussion of youth and parental expectations and preferences regarding adult health care
- **Age 18** – Transition to adult focus of care even if remain in pediatric setting before moving to adult health care
- **Age 18-22** – Transfer of care to adult medical home and specialists with updated medical information, self-care skill assessment, understanding of adult-centered care, decision-making documents, and condition fact sheet, if needed
Algorithm FIRST STEP

Do you have a written transition policy for your practice or clinic or hospital?

• If yes,
  – Are all staff familiar with it?
  – Are all patients familiar with it?

• Why have a transition policy?
  – Ensure consensus
  – Ensure mutual understanding of the processes involved
  – Provide structure for evaluation and audit
Six Core Elements of Health Care Transition

- MCHB’s National Health Care Transition Center (Got Transition, led by Carl Cooley and Jeanne McAllister) developed the Six Core Elements as a quality improvement strategy to align with the Clinical Report algorithm.
  - With a corresponding set of sample tools

- Health Care Transition Indices were also developed as process measures for pediatric and adult practices to correspond with Six Core Elements
  - For each core element, practices assess their level of progress along a continuum from Level 1-4.
## Transition Intervention:  
**Six Core Elements For Practice Transformation**

<table>
<thead>
<tr>
<th>Pediatric Health</th>
<th>Adult Health</th>
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<tbody>
<tr>
<td>1. Transition Policy</td>
<td>1. Young Adult Transition and Care Policy</td>
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<tr>
<td>2. Transitioning Youth Registry</td>
<td>2. Young Adult Patient Registry</td>
</tr>
<tr>
<td>3. Transition Preparation (skills checklist, portable medical summary, fact sheet)</td>
<td>3. Transition Preparation (welcome info, follow up on skills checklist, update portable medical summary)</td>
</tr>
<tr>
<td>4. Transition Planning (create HCT plan)</td>
<td>4. Transition Planning (continue HCT Plan)</td>
</tr>
<tr>
<td>5. Transition and Transfer of Care (check list, shared care with adult provider for period of time)</td>
<td>5. Transition and Transfer of Care (checklist, shared care with pediatric provider as consultant)</td>
</tr>
<tr>
<td>6. Transition Completion</td>
<td>6. Transition Completion</td>
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### Learning collaborative sites

- Washington DC 2011 - 12
- Denver, CO 2011 - 12
- Boston, MA 2011 - 12
- New Hampshire 2012 - 13
- Minnesota 2012 - 13
- Pennsylvania 2012 - 13
- Wisconsin 2012 - 13
DC Learning Collaborative Teams

Howard University Hospital Team

CNMC Children’s Health Center - Adam’s Morgan Team

George Washington University Medical Center Team

Children’s National Medical Center Team

Georgetown University Hospital Team
DC Learning Collaborative Results at 18 Months

✓ Substantial improvements in both pediatric and adult practices
✓ All practices developed a transition policy
✓ All sites developed method for identifying and tracking YSHCN
✓ All sites conducted transition readiness assessments for YSHCN in registry (n = 445)
✓ Transition plans developed for about a third of transitioning youth
✓ 50 youth transferred into adult practices with updated medical summary, transition readiness assessment, sometimes a transition plan and condition fact sheet, and communication between pediatric and adult practices
DC LC Pediatric and Adult Practices

HCT Index Data

Average total score for each core element

#1  #2  #3  #4  #5  #6

Feb-11  Oct-11  May-12
Lessons Learned From DC LC

- Forming partnerships between pediatric and adult practice teams at the beginning is essential
- Transition planning in early adolescence is much easier than transition planning at age 21 and older
- Involvement of nursing, social work, and care coordination staff who are part of clinic processes is critical
- Engagement of consumers is important, but challenging to sustain
- Availability of ready-made tools that can be adapted is very helpful
- Sustainability requires pediatric and adult clinical leadership, EHR integration, and payment mechanisms
Lessons of the collaboratives

• Health care transition has been seen primarily from the pediatric perspective – adult role is unclear at first
  – Role seen as passive reception of transfers
• Twenty-somethings are a special population unrecognized as such in the adult health care system
  – Completely new to the adult system of care
  – Health or health care are not first priorities
  – Variability in developmental readiness
• Medical Home functionalities are helpful
Next Chapter on Transition: Center for Health Care Transition Improvement (CHCTI)

- **Grantee:** The National Alliance to Advance Adolescent Health
- **Project staff:** Peggy McManus, Patience White, Dan Beck, Megan Prior, and Corinne Dreskin
- **Executive team:** Carl Cooley, Jeanne McAllister, Mallory Cyr, Eileen Forlenza, Laura Pickler, Nienke Dosa
- **MCHB project officer:** Marie Mann
Center’s HCT Goals and Year One Priorities

Bringing improved health care transition to scale in large networks...

- Update Six Core Elements and the Health Care Transition Indices
- Partner with 4 Learning Networks to promote spread in large integrated care systems
  - Kaiser (Northern California)
  - Health Partners (MN)
  - Henry Ford Health Systems (MI)
  - Uniformed Health Services Pediatric Hematology Centers
    - (6 sites nationally)
Get Started...Next Week

- Engage senior leaders
- Develop practice, clinic, and hospital level health care transition policies
- Aim to make health care transition support systemic in the entire organization
- Forge relationships with adult providers
- Engage parents, youth, and young adults to inform efforts
- Launch an HCT quality improvement agenda in practices and clinics
Current State of Transition Performance
References

• AAP, AAFP, ACP: A Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs. Pediatrics, 2002, 110:6, 1304


• White, PH, McManus, MA, McAllister, JW, Cooley, WC. A primary care quality improvement approach to health care transition. Pediatric Annals, May 2012, 41:5

• Cooley, WC. Adolescent Health Care Transition in Transition. JAMA Pediatrics, published online August 19, 2013
Resources

• [www.gottransition.org](http://www.gottransition.org)

• cooley@cmf.org