Transitioning Youth to Adult Health Care: New Strategies and Tools for Pediatricians

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CME Disclosure

- We do not have commercial relationships to disclose prior to presenting

- We do not intend to discuss off-label use of FDA-approved products
Learning Objectives

• State the differences between adult-oriented and child-oriented medical care

• Utilize new strategies and tools for transitioning youth

• Define the ICAAP QI model and apply it to transitions care
Project Background

• Goal:
  ▫ To provide high quality, comprehensive, developmentally-appropriate care
  ▫ To help implement a smooth transition from pediatric care to adult-oriented care

• Strategies: develop training curricula for....
  ▫ Pediatricians
  ▫ Internists/Family Physicians/Meds-Peds
  ▫ Include Resources for Youth and Families
  ▫ Develop School-based Curriculum
What is transition?

• The purposeful, planned movement of adolescents and young adults – with or without chronic physical and medical conditions – from a child-centered care model to an adult-oriented health care system.

• Joint Policy Statement from AAP, AAFM, ACP

## National Survey of CSHCN
### Prevalence of CSHCN

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent of children who have special health care needs</td>
<td>14.3</td>
<td>15.1</td>
<td>13.9</td>
<td>2.9% Increase</td>
</tr>
<tr>
<td>Age 0-5 years</td>
<td>9.2</td>
<td>9.3</td>
<td>9.4</td>
<td>-2.1% Decrease</td>
</tr>
<tr>
<td>Age 6-11 years</td>
<td>16.3</td>
<td>17.7</td>
<td>16.2</td>
<td>1.0% Increase</td>
</tr>
<tr>
<td>Age 12-17 years</td>
<td>17.4</td>
<td>18.4</td>
<td>16.3</td>
<td>6.7% Increase</td>
</tr>
<tr>
<td>Male</td>
<td>16.2</td>
<td>17.4</td>
<td>16.0</td>
<td>1.3% Increase</td>
</tr>
<tr>
<td>Female</td>
<td>12.3</td>
<td>12.7</td>
<td>11.8</td>
<td>4.2% Increase</td>
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</tbody>
</table>
## Maternal and Child Health Bureau (MCHB) Core Outcomes

<table>
<thead>
<tr>
<th>MCHB Core Outcome</th>
<th>2009/2010 Illinois %</th>
<th>2009/2010 National %</th>
<th>2005/2006 Illinois %</th>
<th>% Increase or Decrease since 05/06</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN who receive coordinated, ongoing, comprehensive care within a medical home</td>
<td>44.5</td>
<td>43.0</td>
<td>45.1</td>
<td>- 1.3% Decrease</td>
</tr>
<tr>
<td>CSHCN whose families have adequate private and/or public insurance to pay for the services they need</td>
<td>62.1</td>
<td>60.6</td>
<td>59.2</td>
<td>4.9% Increase</td>
</tr>
<tr>
<td>Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence</td>
<td>45.3</td>
<td>40.0</td>
<td>44.2</td>
<td>2.5% Increase</td>
</tr>
</tbody>
</table>
Gaps in Pediatric Care

• Describe, discuss with families

• Assess youth’s transition readiness

• Provide youth with necessary tools

• Identify new primary care source

• Sustainably fund transitions care
Gaps in Care: Adult-oriented Medicine

- Shift from family-centered care to patient–centered care
- Decreased emphasis on developmentally appropriate care
- Lack of familiarity with care coordination needs for YASHCN
- Lack of knowledge about youth-oriented community-based resources
- Lack of knowledge about conditions formerly unseen beyond childhood
Gaps in Care: Special Health Care Needs

• Transition planning is essential

• Patient/family: Leaving long-term provider
  ▫ Emotional aspects
  ▫ Developmentally appropriate care vs. continuity

• Internists/FP: Exam strategies

• Pediatrician: No referral sources

• Guardianship, special education, insurance and community services
Addressing Gaps: ICAAP’S QI Model

• Active learning prepares for improvement
• Assess needs, barriers, resources
• Identify stakeholders in practice
• Provide a menu of options to implement
• Keep it simple
Putting Model into Action

• Assemble QI Team

• Conduct Plan-Do-Study-Act cycles for improvement
  ▫ Small tests of change
  ▫ Re-calibrate as needed

• Emphasis on parent/patient involvement

• Goals: Improve care for patients and improve work flow for staff
ICAAP’s Evidence Base for QI Model

ICAAP lead medical home staff received formal training on the Model for Improvement from the Institute for Healthcare Improvement and NICHQ. Lessons applied to ICAAP programs:

- Illinois Medical Home Project Phase 1 (2004 to 2006) and Phase II (2007 to 2009)
- Coordinating Care with Early Intervention Project (2009 to 2011)
- Building Community-Based Medical Homes for Children Program (2009-2011)
- Illinois Healthy Beginnings II Pilot (2010- present)
- Building Medical Homes for the Ambulatory and Community Health Network (2011 – present)
- CHIPRA Demonstration Grant (2010 to present)
What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Model for Improvement

Act

Plan

Study

Do
Measurement: Types & Time

Hunches
Theories
Ideas

PDSA Measures

Changes That Result in Improvement

Process Measures

Outcome Measures

PDSA Measures

DATA

APSD

APSD

APSD
Tips for Measurement

Plot data over time: “Tracking a few key measures over time is the single most powerful tool a team can use.”
Building the Transitioning Youth to Adult Health Care Course

• Content developed by practicing providers, youth and families
  ▫ Pediatric Training to Prepare for Transfer
  ▫ Internist/FP Training to Receive New Patients
  ▫ Tools for Youth and Families

• Applied model to create implementation tools
  ▫ Aims Statements and QI Strategies
  ▫ Barriers/Ideas for Change
  ▫ Key Clinical Activities
Pediatric Provider Training
Introduction
Develop/maintain registry
Provide/explain written transition policy
Assess health care skills
Review individualized transition goals
Provide benefit and services information sources
Discuss need for guardianship for patients with intellectual disabilities
Provide portable medical summary
Help identify adult primary care physician
Coding and reimbursement
Conclusion

Adult Provider Training
Introduction

Part 1- Transitional Care
Develop and maintain a registry
Determine developmental level and assess health care skills
Review individualized health care skills goals
Request a medical summary for new patients
Request information from other providers
Create/maintain patient’s medical summary
Provide information sources on adult benefits and services
Coding and reimbursement

Part 2- Caring for YSHCN
Identifying special needs and planning accommodations
Examining youth with behavioral and/or cognitive impairments
Examining youth with mobility limitations
Discussing the need for guardianship
Clinical information on common conditions
Conclusion
# Illinois Healthcare Transition Project

## Training Modules and Handouts

<table>
<thead>
<tr>
<th>Patient/Family Handouts</th>
<th>Portable Medical Handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teen Checklist</td>
<td>Summary</td>
</tr>
<tr>
<td>Caregiver Checklist</td>
<td>Transition Brochure</td>
</tr>
<tr>
<td>Differences in Care</td>
<td>Managing Medications</td>
</tr>
<tr>
<td>Do You Understand</td>
<td>Medical Emergency</td>
</tr>
<tr>
<td>Insurance</td>
<td>Transition Timeline</td>
</tr>
<tr>
<td>Filling a Prescription</td>
<td>Transition to Adulthood-</td>
</tr>
<tr>
<td>Finding Adult Providers</td>
<td>Parents and Caregivers</td>
</tr>
<tr>
<td>Guardianship</td>
<td>Transition to Adulthood-</td>
</tr>
<tr>
<td>Healthcare Transition</td>
<td>Teens and Young Adults</td>
</tr>
<tr>
<td>How Well Do You Know</td>
<td>Working with Your Doctor</td>
</tr>
<tr>
<td>Your Healthcare Needs</td>
<td></td>
</tr>
</tbody>
</table>
### Example of an Aim and Measure

**Measuring Your Practice’s Transition Planning Performance**

<table>
<thead>
<tr>
<th>Suggested Aim</th>
<th>Data Collection Question</th>
<th>Measure</th>
<th>Suggested Goal</th>
</tr>
</thead>
</table>
| **Provide/explain the practice's transition policy to the patient and family for 90% of patients ≥14 years. The written policy should include the suggested age and process by which the youth will shift to an adult model of care.** | For youth ≥14  
1. Has the practice's transition policy been provided/explained to the patient and family? (Note: AAP recommends that this is done at age 12):  
- Yes  
- No | Name: Provide/explain written transition policy  
Source: Question 1, shown at left  
Numerator (x): Total number of patients ≥14 years who have received a written transition policy that has been explained to them (Yes answer to question 1)  
Denominator (y): Total number of charts in chart set | 90% |

Benchmarks not available at this time; however, this QI project and others may help establish benchmarks for transition activities in the future.
**Example of an Aim and Measure**

| Use the Transition Checklist for Teens and/or Transition Checklist for Parents/Caregivers to assess the health care skills of 70% of youth ≥14 years every 12 to 24 months. | For youth ≥14 | Name: Assess health care skills  
Source: Question 2, shown at left  
Numerator (x): Total number of patients ≥14 years or caregivers who have had their health care skills assessed within the past 12 to 24 months (Yes answer to question 2)  
Denominator (y): Total number of charts in chart set | 70% |
<table>
<thead>
<tr>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have the patient's and/or caregiver’s health care skills been assessed using a tool such as the Transition Checklist for Teens and/or or Transition Checklist for Parents/Caregivers within the past 12 to 24 months? (Note: AAP recommends that this is done annually.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ No</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Transition Planning Checklist

**Patient Name:** ______________________________________  **Date of Birth:** __________________________  **Anticipated age of transition:** _____

**Directions:** Attach this checklist to the patient’s chart (or consider how to adapt into your EHR) to guide transition planning efforts and ensure milestones are met in a timely manner. Use the Notes column to record information such as dates, names, information provided, or next steps.

<table>
<thead>
<tr>
<th>Recommended Action</th>
<th>By Age</th>
<th>✓ If Complete or N/A</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Provide/explain written transition policy</td>
<td>12</td>
<td>◐</td>
<td></td>
</tr>
<tr>
<td>2. Assess health care skills</td>
<td>14, then annually</td>
<td>◐</td>
<td></td>
</tr>
<tr>
<td>3. Set/prioritize/review individualized transition goals</td>
<td>14, then annually</td>
<td>◐</td>
<td></td>
</tr>
<tr>
<td>4. Discuss need for adult insurance; provide information sources as needed</td>
<td>17</td>
<td>◐</td>
<td></td>
</tr>
<tr>
<td>5. Discuss need for adult benefits and services; provide information sources as needed</td>
<td>17</td>
<td>◐</td>
<td></td>
</tr>
<tr>
<td>6. Discuss need for guardianship if patient has intellectual disabilities</td>
<td>14</td>
<td>◐</td>
<td></td>
</tr>
<tr>
<td>7. Create/update/maintain patient’s portable medical summary</td>
<td>17, then at routine visits</td>
<td>◐</td>
<td></td>
</tr>
<tr>
<td>8. Identify adult physicians</td>
<td>17</td>
<td>◐</td>
<td></td>
</tr>
</tbody>
</table>
Transitions Web-Based Courses

• Available any time, for any provider

• CME and MOC tracks

• Track improvement as individual or as practice

• Designed to support doing
Tools Unique to Web

• QI Planning Course Document
  ▫ Learner applies concepts to their practice
  ▫ Identify practice-specific barriers/resources

• Videos
  ▫ Multiple experts

• Resource library

• Interactive communication with other participants
Pediatric Training

- Offers 15 CME credits
- Offers 25 Pediatric Maintenance of Certification Part IV credits
- Open to all late 2012
- Utilizes proven, successful strategies from ICAAP QI Model
Adult-Oriented Provider Training

• Scheduled to go live late 2012

• Exam strategy demonstration videos

• Goals:
  ▫ Increase number of providers who accept YASHCN
  ▫ Help prepare adult-oriented providers to care for YASHCN
Using On-Line Course

- Complete presentations
- Determine activities to implement
- Begin activities
- Periodic progress review
Highlights from Web Course

5. Which of the example policies can you adapt for your practice?

6. List any potential barriers to implementing a transition policy in your practice:

   No Response entered for this question.

7. Ideas include e-mailing the checklist to them before an appointment, asking them to complete in the waiting room before an appointment, or scheduling a separate visit with office staff to complete.
Highlights from Course

Transitioning Youth to Adult Health Care for Pediatric Providers

Assess Health Care Skills

Sampling Baseline (40)% Goal (70)%

Cycles

1 2

Return Training Menu

Export to PDF
Export to XLS
### Highlights from Course

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess Health Care Skills</td>
<td>Cycle 1</td>
<td>Cycle 2</td>
</tr>
<tr>
<td>Chart Data: Improvement</td>
<td>5/7/2012</td>
<td>5/7/2012</td>
</tr>
<tr>
<td>Chart Data: No Improvement</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Chart Data: Not Applicable</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Denominator</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>% Change</td>
<td>50%</td>
<td>30%</td>
</tr>
<tr>
<td>Discuss Need for Insurance, Benefits, and Services Information</td>
<td>Cycle 1</td>
<td>Cycle 2</td>
</tr>
<tr>
<td>Chart Data: Improvement</td>
<td>5/7/2012</td>
<td>5/7/2012</td>
</tr>
<tr>
<td>Chart Data: No Improvement</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Chart Data: Not Applicable</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Denominator</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>% Change</td>
<td>90%</td>
<td>80%</td>
</tr>
<tr>
<td>Create or Update/Maintain a Portable Medical Summary</td>
<td>Cycle 1</td>
<td>Cycle 2</td>
</tr>
<tr>
<td>Chart Data: Improvement</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Chart Data: No Improvement</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Chart Data: Not Applicable</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Denominator</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>% Change</td>
<td>70%</td>
<td>90%</td>
</tr>
</tbody>
</table>
Citations

- Reiss and Gibson, 2002; 2: 2004 NOD/Harris Survey; Kentucky HRTW project

- National Survey for Children with Special Health Care Needs, 2009/10 and 2005/06, Maternal and Child Health Board, Health Resources and Services Administration


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