Paving the Way between Pediatric and Adult Health Care for Youth and Young Adults

Ready to Launch....Countdown to Success
Arizona 17th Annual Transition Conference
Arizona Department of Education
Scottsdale, Arizona
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Sarah Savage Cooley
• Poet
• Speaker
• Activist
• Author

She “opens a window into her heart and provides a portrayal of what it means to be human.”

Her writing illustrates the emotions and reflections of a woman who embraces all aspects of life.

Follow Sarah’s story and work at: www.sarahsavagecooley.com

Purchase her work at: www.etsy.com - search Sarah Savage Cooley
PREPARE TO TRANSFER!
• Are you familiar with the guidance for health care transition published by the AAP, AAFP, and ACP in a clinical report in 2011?*

• *Cooley, WC, Sagerman, P. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics July 2011
• Are you familiar with the Six Core Elements of Health Care Transition* that operationalize the guidance of the 2011 clinical report?

• *www.gottransition.org
• Are you currently involved in a health care transition improvement project in a setting where you work or receive care?

• Have you considered how health care transition should fit into other adult transition planning?
“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?”
Principles

• The transition to adulthood is a complex process that:
  – Is non-linear
  – Involves interrelated, non-sequential steps
    • Occurring with variable timing and duration
  – Has outcomes that are not predictable
Principles

• The transition to adulthood is not an action taken by health care providers, educators, administrators, or policy makers

• It is a complex, multi-faceted life experience of the young adult

• We do not ”transition patients”
  – We may transfer their care to new providers
  – And/or, invoke with them an adult model of care

• Transition does not end with a transfer of care
Principles

• Health care transition...
  – Involves a movement from pediatric settings and pediatric models of care to adult settings and adult models of care
  – Must have mindful preparation, planning, and follow-through
  – Must be made relevant to the youth’s personal goals, interests, and plans for adult life
  – Needs to be integrated as much as possible with other dimensions of an individual’s adult transition (education, work, housing, recreation, etc)
Simultaneous Transitions

• From pediatric child-centered care to adult oriented health services
• From living at home with family to living in the community
• From school to work
• Towards adult relationships

“Diseases of childhood are now considered diseases of childhood onset” – Rosen 1995

<table>
<thead>
<tr>
<th>Disease</th>
<th>1970’s</th>
<th>2000’s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood Cancer</td>
<td>25% 5y survival</td>
<td>80% 5y survival</td>
</tr>
<tr>
<td>Congenital Heart</td>
<td>59% survival</td>
<td>85% survival</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>7 years old</td>
<td>35 years old</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>20 years old</td>
<td>55 years old</td>
</tr>
<tr>
<td>Sickle Cell Disease</td>
<td>9 years old</td>
<td>46 years old</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>&lt;20 years old</td>
<td>60+ years old</td>
</tr>
</tbody>
</table>

Rosen D. J of Adol Med. 1995
Healthcare Transition

Adolescent
- Developmental level
- Learning style
- Motor skills
- Mental Health

Family
- Health literacy
- Family health
- Finances

School
- Voc/Ed
- Living skills
- Behavior support

Health Providers
- Knowledge
- Medical home
- Institutional support
- Financial/Insurance support

Community
- Supported living
- Case facilitation
- Voc rehabilitation
Principles of Health Care Transition  
(When)

1. A planned coordinated approach is essential.
2. Transfer should occur at a time of disease stability.
3. When possible, the transferring and receiving teams should meet together with the patient and family.
4. The adolescent/young adult should be continuously encouraged to increase their self-reliance and self-care well prior to the anticipated transfer time.
5. Family should actively transition their roles from direct caregivers to advocates and supporters.
6. Professional sensitivity to psychosocial issues of disability.
8. Family support.
9. Professional and environmental or institutional support for the concept of transition.

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>
</tr>
</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 within a medical home</td>
</tr>
<tr>
<td><strong>40%</strong></td>
<td>receive services needed to make appropriate transitions to adult health care, work, and independence</td>
</tr>
</tbody>
</table>

**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
Gaps in Needed Transition Services For YSHCN

• 18 million adolescents in the US, ages 18-21*
  – 25% have chronic conditions**
• Most youth and families are ill-prepared to transition to adult centered care.
  – 60% of YSHCN are not receiving needed transition services**
  ▪ Without transition services***
    – Health is diminished
    – Quality of care is compromised
    – Costs are increased
• Surveys of health providers show they lack a systematic way to support youth and families in transition from pediatric to adult health care.

## Health Care Utilization Changes During Transition Years

<table>
<thead>
<tr>
<th>Health Care Utilization</th>
<th>0-17</th>
<th>18-24</th>
</tr>
</thead>
<tbody>
<tr>
<td>• No Office/MD Visit in Past Year</td>
<td>8.1%</td>
<td>27.2%</td>
</tr>
<tr>
<td>• No Preventive Care in Past Year</td>
<td>24.7</td>
<td>55.3</td>
</tr>
<tr>
<td>• ED Visit in Past Year</td>
<td>18.1</td>
<td>21.5</td>
</tr>
</tbody>
</table>

Source: 2013 National Health Interview Survey: Special tabulations prepared by State Health Access Data Assistance Center
More Reasons for Concern

- Majority of existing “transition programs” are based in children’s hospitals often in specialty clinics or limited to subset of youth with complex needs
- Small evidence base for specific transition interventions
- No consensus on transition outcome measures
- Majority of pediatric and adult care providers in separate systems with limited clinical interaction
- Limited wide-spread awareness of the problem of pediatric to adult care transitions
State of Health Care Transition from Pediatric to Adult Health Care Approaches
HOW TO GROW UP
AAP/AAFP/ACP Clinical Report on Health Care Transition*

- In 2011, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- Targets all youth, beginning at age 12
- Algorithmic structure with:
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
- Extends through transfer of care to adult medical home and adult specialists

<table>
<thead>
<tr>
<th>Age</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Youth and family aware of transition policy</td>
</tr>
<tr>
<td>14</td>
<td>Health care transition planning initiated</td>
</tr>
<tr>
<td>16</td>
<td>Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care</td>
</tr>
<tr>
<td>18</td>
<td>Transition to adult approach to care</td>
</tr>
<tr>
<td>18-22</td>
<td>Transfer of care to adult medical home and specialists with transfer package</td>
</tr>
</tbody>
</table>

*Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home (*Pediatrics*, July 2011)
Got Transition

• Funded by Maternal and Child Health Bureau
• Operated by The National Alliance to Advance Adolescent Health
• Activities:
  1) HCT QI Spread
  2) HCT Title V TA and Health Professional Education
  3) Young Adult and Family Engagement
  4) HCT Policy Interventions
  5) Information Dissemination
Health Care Transition Goals

- To improve the ability of youth and young adults to manage their own health and effectively use health services

- To ensure an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care
Six Core Elements of Health Care Transition: QI Model

• Original Six Core Elements (1.0), developed in 2011 by Carl Cooley and Jeanne McAllister, as QI strategy based on AAP/AAFP/ACP Clinical Report with set of sample tools and measures.

• HCT Learning Collaboratives (with primary and specialty care practices)
  – Conducted between 2010-2012 in DC, Boston, Denver, New Hampshire, Minnesota, Wisconsin
  – Used evidence based Learning Collaborative methodology pioneered by Institute for Healthcare Improvement
  – Demonstrated Six Core Elements and tools feasible to use in clinical settings and resulted in improvements in transition process*

* McManus et al. *Journal of Adol Health* 56:73 2014
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
Updated Version of Six Core Element Tools

- Published in 2014
- Based on learning collaboratives in DC, MA, NH, WI, MN
- Reviewed by over 100 clinical (primary and subspecialty providers, nurses, nurse practitioners, PAs and social workers) and consumer experts
- Represents state-of-the-art (process and tools)
- New Six Core Elements have three packages with expanded measurement options and tools for core element and can be used by all members of the health care team.
- 5th grade reading level, Spanish translation available
- CUSTOMIZABLE, USE YOUR OWN LOGOS
- FREE (download from www.gottransition.org)
Six Core Element Approach to Health Care Transition

- **Discuss Transition Policy**
  - **AGE 12-14**
  - **AGES 14-18**

- **Track progress**
  - **AGES 14-18**

- **Assess transition readiness skills**
  - **AGES 14-18**

- **Develop transition plan with medical summary/emergency care plan**
  - **AGES 14-18**

- **Transfer adult approach to care**
  - **Transfer documents**
  - **Integration into adult practice**
  - **AGES 14-18**

- **Confirm completion**
  - **Consumer feedback**
  - **Ongoing Care**
  - **AGES 18-26**

**1** Transition Policy

**2** Transition Tracking and Monitoring

**3** Transition Readiness

**4** Transition Planning

**5** Transfer of Care/Adult Model of Care

**6** Transition Completion/Ongoing Care
Six Core Elements 2.0

Transitioning Youth to Adult Health Care Providers
(Pediatric, Family Medicine, and Med-Peds Providers)

Transitioning to an Adult Approach to Health Care Without Changing Providers
(Family Medicine and Med-Peds Providers)

Integrating Young Adults into Adult Health Care
(Internal Medicine, Family Medicine, and Med-Peds Providers)
CORE ELEMENT #1: POLICY
(Pediatric Practice Example)

• **Purpose**: Formalize approach, reduce clinician variability, offer transparent approach to youth and families

• **Content**:  
  – Define practice approach and recommended ages for transition preparation for adult-focused care, transfer, and integration into adult care  
  – Clarify adult approach to care and legal changes at age 18  
  – Reading level should be appropriate

• **Post**: Communicate it to all involved early in the process
Core Element #2: Transition Tracking and Monitoring (Pediatric Practice Example)

- **Purpose**: Facilitate systematic data collection to improve quality at individual and population levels

- **Content**:
  - Demographic and diagnostic/complexity data
  - Date of receipt of each core element (e.g., policy shared, readiness assessment administered, etc.)

- **Format**: paper check list, excel spread sheet, EHR
TRANSITION READINESS
Core Element #3: Transition Readiness (Pediatric Practice Example)

• **Purpose:** assess the youth’s skills to manage their health/health care in the adult approach to care and (self-care skills assessment available in adult package)

• **Content:**
  - Ranks importance of changing to adult provider before age 22
  - Ranks confidence about ability of changing to adult provider
  - Assesses self-care skills related to own health and using health care services

• **Use:**
  - Completed several times during the transition process
  - Used as a discussion tool to plan skill building education
  - Does not predict transition success
  - Customized to meet the needs of the practice’s population
TRANSITION PLANNING
Core Element #4: Transition Planning
(Pediatric Practice Example)

• **Purpose:** Establish agreement between youth and provider about set of actions to address priorities and access current medical information

• **Content:**
  - Identify what matters most to youth in becoming adult beyond health goals
  - Define how learning about health and health care supports youth’s over all goals (add readiness assessment skill needs to the plan)

• **Complete portable medical summary and emergency care plan with “special information” for adult provider**
  - Include non medical information that the youth and family want to share and will assist the adult provider to engage the youth easily
TRANSFER OF CARE
Core Element #5: Transfer of Care
(Pediatric Practice Example)

• **Purpose**: Ensure completion and sharing of transfer package with adult provider and support engagement of young adult with a new provider

• **Content**:
  
  – Transfer letter, clarifying coverage of youth’s care until initial adult visit with transfer package
  
  – Communicate directly with the adult provider, send transfer package with the last readiness assessment, plan of care, medical summary and emergency care plan, condition fact sheet, guardianship doc., and offer consultation.
TRANSFER COMPLETION + ONGOING CARE
Core Element #6: Transfer Completion
(Pediatric Practice Example)

• **Purpose**: Confirms initiation of the new adult provider and the ending of pediatric role, except as consultant

• **Content**:
  – Communicate with adult practice confirming completion of transfer
  – Obtain consumer feedback anonymously after last pediatric visit (example feedback form at gottransition.org)
State Title V agencies and HCT

– In 2016, 32 state Title V agencies are developing action plans to increase the percentage of adolescents with and without special health care needs who receive services necessary to make transitions to adult health care.

• AL, AR, AZ, CA, CT, DC, FL, GA, HI, IA, IN, IL, KY, LA, MA, MD, MI, MN, MT, ND, NJ, NM, NY, OK, OR, RI, TN, TX, UT, VA, WI, WY
States’ Transition Strategies

- Improve the implementation of the Six Core Elements of HCT (in Title V programs, clinical settings, health plans)
- Increase the # of health care providers and consumers participating in HCT QI initiatives involving BOTH pediatric and adult practices using the Six Core Elements
  - 21 out of 32 states with HCT priority are using the Six Core Elements as their framework and toolkit for providers
- Increase the # of health care providers who participate in HCT education and training on evidence-based HCT strategies
What to do? Where to start?
Get Started…Next Week

• Consider your organization’s approach to health care transition
• How can health care transition fit into a school curriculum?
• How can/should health care transition be addressed in an IEP’s transition plan?
• What other community agencies or resources should be involved in improving health care transitions?
• What is the role of school nurses? Of school-based health clinics?
• Engage parents, youth, and young adults to inform efforts
Want more information?
Got Transition: federally funded resource center on HCT
www.gottransition.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


• 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
Thank You and Questions
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HealthCareTransition @GotTransition2