Difficulties in Transition: View from US Pediatrics

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DC Health Care Transition Learning Collaborative
Learning Objectives

• US Transition Context - Transition Definition and 2002 Consensus Statement from AAP/ACP/AAFP on Transition
• Pediatricians’ comments on transition when asked by youth and colleagues
• National surveys of US State officials and American pediatricians on barriers to transition and services offered
• A view of the cultural gap between pediatric and adult medicine
What is Health Care Transition?

Transition is the deliberate, coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals.

Components of successful transition

- Self-Determination
- Person Centered Planning
- Prep for Adult health care
- Work /Independence
- Inclusion in community life
A Consensus Statement
Health Care Transitions for Young Adults With Special Health Care Needs (2002)

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians - American Society of Internal Medicine

1. Identify primary care provider
2. Identify core knowledge and skills
3. Maintain an up-to-date medical summary that is portable and accessible
4. Develop an individualized transition plan
5. Apply preventive screening guidelines
6. Ensure affordable, continuous health insurance coverage
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US Pediatricians’ Comments

• When Will I move to an adult doctor (16-18 year olds)?
  – “we will talk about it later”
  – “You do not have to worry about it”
  – “the adult doctors will not care for you the way I do/not as nice as we are”
US Pediatricians' Comments

• Do you transfer your patients to adult providers?
  – “I cannot find any adult providers to care for my children (patients)”
  – “There is no adult equivalent of my specialty so I cannot transfer my patients”
  – “The adult physicians do not take the time to adequately care for my complex patients”
  – “The families do not want to go and they always come back if I send them away to adult providers”
  – “They (adult providers) think they can take care of my patients but they can’t”
US Pediatricians’ Comments

• When will you plan to transfer your patients to an adult provider?
  – “After the child graduates from College we tell them they need to find a doctor for adults”
  – “Maybe...in the future....in their 20s”
  – “Now, if I could find someone to care for my complex older patients”
  – “When they (the patients) become pregnant”
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States which

- listed transition as a priority 22 (37%)
  before 2000 – only 6 (AL, AR, KY, NE, NM, SC)

- discussed the need for health care transition 37 (63%)

- reported youth involved in developing the state needs assessment 9 (15%)
States Title V agencies provide/have

- care coordination should 81%
  include health transition planning

- designated state level transition coordinator 48%

- contract language for clinics 33%
  related to transition
## Self-Rating of Transition Processes by State Title V Agencies - 2005

**HRTW Survey N=41 states/territories (1 blank)**

<table>
<thead>
<tr>
<th>Rating Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have transition policy and processes integrated into practice</td>
<td>12%</td>
</tr>
<tr>
<td>Working on; about halfway to where want to be</td>
<td>26%</td>
</tr>
<tr>
<td>Beginning stages</td>
<td>48%</td>
</tr>
<tr>
<td>No processes, but interested</td>
<td>12%</td>
</tr>
<tr>
<td>Not interested, too busy, no resources</td>
<td>0%</td>
</tr>
<tr>
<td>State Title V Progress on Transition to Adulthood</td>
<td>% (N = 49)</td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Report transition training for state staff</td>
<td>91% (46)</td>
</tr>
<tr>
<td>Have requirement of formal transition planning for youth in state clinics or clinics supported by Federal Title V grants</td>
<td>69% (34)</td>
</tr>
<tr>
<td>Report transition as part of quality assurance activities</td>
<td>28% (14)</td>
</tr>
</tbody>
</table>
2008 National Survey of US Title V State Agencies

• Areas of technical assistance most requested:
  
  – Transition planning (tools and templates for transition planning including emergency plans and portable medical summaries)
  
  – Assessments/education for transition readiness for youth, families, and professionals/practice
  
  – Youth Advisory Councils
  
  – Recruiting and supporting adult health care providers
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Barriers to transition care for US Pediatricians (both major and minor barriers combined)*:

- 88% lack of knowledge of community resources
- 85% fragmentation of adult health care
- 84% lack of adolescent knowledge about their health condition and skills to self advocate during health care visits
- 80% lack of adult primary care and specialty providers
- 80% difficulty breaking bond with adolescents and parents
- 79% lack of office staff skills and processes in transition
- 76% lack of reimbursement for transition activities

*2008 AAP Periodic Survey # 71
US Pediatricians Actions around Transition*
(for all or most of their adolescent patients)

• 47% assisted with a referral to family or internal medicine
• 45% Refer to adult specialists
• 33% discussed consent and confidentially issues prior to age 18
• 32% Assist with finding an adult medical primary care doctor
• 27% Create a portable medical record summary
• 23% offered education and consultative support to families or adult providers
• 19% assisted in identifying insurance options after age 18
• 12% create an individualized health care transition plan

* 2008 AAP Periodic Survey# 71
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Prepare for the Realities of Health Care Services
Moving from Pediatric to Adult Health Systems

Difference in System Cultural Practices

- **Pediatric Services:** Family Driven
- **Adult Services:** Consumer Driven

The youth and family finds themselves between two medical worlds ......that often do not communicate....
<table>
<thead>
<tr>
<th>Age-related</th>
<th>Pediatric</th>
<th>Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Growth &amp; development, future focussed</td>
<td>Maintenance/decline: Optimize the present</td>
<td></td>
</tr>
<tr>
<td>Focus</td>
<td>Family</td>
<td>Individual</td>
</tr>
<tr>
<td>Approach</td>
<td>Paternalistic Proactive</td>
<td>Collaborative, Reactive</td>
</tr>
<tr>
<td>Shared decision-making</td>
<td>With parent</td>
<td>With adult patient</td>
</tr>
<tr>
<td>Services</td>
<td>Entitlement</td>
<td>Qualify/eligibility</td>
</tr>
<tr>
<td>Non-adherence</td>
<td>&gt; Assistance</td>
<td>&gt; tolerance</td>
</tr>
<tr>
<td>Procedural Pain</td>
<td>Lower threshold of active input</td>
<td>Higher threshold for active input</td>
</tr>
<tr>
<td>Tolerance of immaturity</td>
<td>Higher</td>
<td>Lower</td>
</tr>
<tr>
<td>Coordination with federal systems</td>
<td>Greater interface with education</td>
<td>Greater interface with employment</td>
</tr>
<tr>
<td>Care provision</td>
<td>Interdisciplinary</td>
<td>Multidisciplinary</td>
</tr>
<tr>
<td># of patients</td>
<td>Fewer</td>
<td>Greater</td>
</tr>
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Muchas Gracias!

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