The Road to Transition: Roadmaps, Roadblocks, and Roadside Assistance

Miriam Kalichman, MD
Associate Medical Director
Division of Specialized Care for Children
Children’s Habilitation Clinic
Disclosure of Relevant Financial Information

- I have no relevant financial information to disclose

- This presentation will not include discussion or pharmaceuticals or devices that have not been approved by the FDA.
Goals

- Identify what pediatricians can do to promote transition in teens with disabilities and chronic illness
- Identify obstacles to transition
- Identify resources to assist with transition
Integrated Systems of Services for IL Children and Youth with Special Health Care Needs

- Funded by Maternal and Child Health Bureau
- Project period: 6/1/09 through 5/31/12
- Administered by ICAAP in collaboration with DSCC
- Goal: Improve access to high-quality, comprehensive health care for young adults with disabilities and chronic health conditions and ensure that youth receive the services necessary for a successful transition to adulthood
What is transition?

- Orderly process of transfer from one system of care and services to another
- Planned and implemented in cooperation with the patient and family consistent with “Medical Home” principles
Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs- AAP, AAFP, ACP-ASIM (2002)

- Have a health care manager who coordinates health care planning between pediatric and adult health care providers
- Provide transition training to enhance the knowledge and skills of primary care adult physicians
- Formulate a medical summary for transfer to adult primary and specialty physicians
- Develop a health care transition plan beginning at age 14
- Ensure primary and preventive care based on accepted medical guidelines
- Ensure continuous health insurance coverage
Current transition outcomes

Young adults with disabilities:

- Have poorer health status
- Have higher annual use of emergency care (40% vs. 25% of typical young adults)
- Are more likely to require care not covered by their insurance (28% vs. 7%)
- Are more likely to go without needed care (18% vs. 7%)
- Approximately 15,000 patients over 21 years old continue care at pediatric hospitals annually

2004 NOD/Harris Survey; Kentucky HRTW project
### Transition Services Offered in Pediatric Practices to Adolescents with Special Needs

<table>
<thead>
<tr>
<th>Transition Services</th>
<th>For all or most</th>
<th>For some</th>
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</thead>
<tbody>
<tr>
<td>Assistance with referral to family or internal medicine physician</td>
<td>47%</td>
<td>33%</td>
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<tr>
<td>Assistance with referral to adult specialists</td>
<td>45</td>
<td>32</td>
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<tr>
<td>Discussion of consent and confidentiality issues prior to age 18</td>
<td>33</td>
<td>27</td>
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<tr>
<td>Assistance with medical documentation for program eligibility</td>
<td>32</td>
<td>34</td>
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<tr>
<td>Assistance in creating a portable medical summary</td>
<td>27</td>
<td>26</td>
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<tr>
<td>Education and consultative support to family or internal medicine physicians</td>
<td>23</td>
<td>30</td>
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<tr>
<td>Assistance with identifying insurance options after age 18</td>
<td>19</td>
<td>22</td>
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<tr>
<td>Assistance in creating an individualized health care transition plan</td>
<td>12</td>
<td>26</td>
</tr>
<tr>
<td>Provision of packet or handouts to adolescent/parents</td>
<td>11</td>
<td>14</td>
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McManus et al., AAP Periodic Survey of Fellows #71, 2008
Elements of transition

- Family, patient, and care provider awareness of need and timeline
- Explicit assignment of tasks/processes to each person involved
- Resource identification
- Skill building (patient, family, care providers on both ends)
- Assumption of care
- Feedback
Transition from the doctor’s point of view

- “Giving up” a patient
- Concerns about loss of continuity
- Concerns about one’s own loss of control
- Concerns about whether someone else will care as much
- Concerns that another physician isn’t available and you will practice beyond your skill level
Transition from the patient’s point of view

- May be a time to develop a new identity, like changing schools or going to college
- Discomfort at being handled by and speaking with a new provider
- Concern about expertise of new provider in general and about one’s own issues in particular
- Loss of support from a team that has been in place for years
Transition from the family’s point of view

- Will I be excluded?
- Can my child really make decisions?
- Insurance/financial issues
- Guardianship—does he need it? Do I want it?
- Will they take care of my child?
Transition from the receiving end

- How hard is the patient?
- How will I get paid?
- What if I don’t know anything about the disease?
- How do I work with the family?
- What if I don’t know the resources?
Getting started with patients and families

- All transitions begin in infancy—“when you grow up”
- Addressing self-care and self-management at every visit
- Teaching parents to keep records
- Trying to get family involvement in groups that work with adults with the same type of problem
Moving on with patients

- Goal setting—by the next visit, what do you think you can do to take care of your own....
- What do you want to do when you grow up?
- Did you go to your IEP (14.5 years)?
- Individual time with the patient
- If patient needs help, can the patient direct you to help him
More readiness ideas

- Can the child give his history, meds, allergies?
- Can the child direct his personal care?
- Can the child tell time?
- Can the child make his own appointment? Travel alone? Use the phone? Order his supplies? Take his own medication?
- Therapy directed at these skills rather than range of motion
Working with the parents

- Do they have internists?
- Have they asked?
- Getting the parents out of the room
- Involving the patient in decisions
- Clearly explaining competence and guardianship
Getting started with colleagues

- Cultivate relationships with FPs and internists: all of your patients will grow up
- Try to get appropriate consultations, even if just curbside, on interesting cases
- Keep a resource directory of your own
- For specific referrals, start with the easy ones
Strategies for transitioning care

- Start early (by age 14)
- Assess medical service needs
  - Services currently being used
  - Services needed in the future - primary and specialty
- Develop a written health care transition plan
- If possible, work with a transition or care coordinator
- Develop a Portable Medical Summary
- Encourage a visit and interview with the new physician
- Have a period of co-management, if possible
- Have an agreed transfer date - reduces confusion and makes it clear who is responsible
- Incorporate principles from adolescent medicine
  - Confidential care, routine psychosocial and health risk assessment, promote self-management
- Be flexible
Roadblocks

- Insurance: Few private providers take Medicaid, high number of chronically ill and disabled people on Medicaid
- Time: Time is money, people who talk or move slowly or are in the room a long time are expensive to care for
- Lack of experience: Minimal experience for most general internists with young adults or people with disabilities
More roadblocks

- Physical barriers in the office
- Environmental issues in the office (noise, set up for people who arouse unwanted interest)
- Lack of acquaintance with appropriate consultants
Communication roadblocks

- From the patient point of view, lack of personal engagement/ unwillingness to pry or chase
- From the MD point of view, patient may not accept a locus of control. If you don’t show up, that is your responsibility
- Who is the keeper of the information—patient or family?
Roadside bombs

- An adult patient a pediatrician is caring for develops an adult disease (coronary artery disease, prostate problems, pregnancy, malignancy)
- A pediatrician handles an adult patient as he would a child patient without recognizing important adult co-morbidities
- A patient without a guardian needs one in a hurry
- Neglect of a medically complex adult
Roadside assistance

- Community independent living associations
  - IL Network of Centers for Independent Living

- Legal clinics
  - Health and Disability Advocates
    - [http://www.hdadvocates.org/](http://www.hdadvocates.org/)

- Social Security Administration- SSI at age 18
  - 1-800-772-1213
  - [www.socialsecurity.gov](http://www.socialsecurity.gov)

- The Arc of Illinois and Family to Family- excellent resources
  - [http://www.thearcofil.org/](http://www.thearcofil.org/)
  - 866-931-1110 toll free
  - familytofamily@thearcofil.org
Roadside assistance

- Illinois Assistive Technology Program
  - http://www.iltech.org/
- Illinois Worknet
  - Illinois Employment Training Centers
  - http://www.illinoisworknet.com
Roadside assistance

- Rehabilitation hospitals
- DRS- should be done through school
- Other parents/families
- Disease specific organizations
- Vendors
- Guardianship and estate planning if needed
Roadside assistance

IL Department of Human Services
1-800-843-6154 (find a local office)
www.dhs.state.il.us

- Division of Developmental Disabilities-1-888-DDPLANS; www.dd.illinois.gov
  - In-home supports, respite, training programs, job coaches, living arrangements, adaptive equipment, PUNS

- Family Community Resource Centers- call DHS for local office
  - Apply for Medicaid

- Division of Rehabilitation Services
  - Vocational, Educational, and Home Services- call DHS

- Division of Mental Health- call DHS
  - Mental health services, employment and housing assistance
Roadside assistance

Social Security Administration

- Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI)
- Work Incentive Planning and Assistance
  - PASS, Ticket to Work
  - 1-800-807-6962
  - http://www.illinoisworknet.com/vos_portal/?partner=
- Community Work Incentive Coordinator (CWIC)
  - 1-800-772-1213
  - www.socialsecurity.gov
Obtaining health insurance

- Employer-based group coverage - own coverage
  - Best option if employed with benefits
- Employer-based group coverage - remain on family plan
  - Up to age 26
  - OR lifetime coverage if condition occurred before limiting age and individual is dependent on care provider for lifetime (requires residential services)
- Private plan purchased by individual
- IL Comprehensive Health Insurance Plan
  - If denied due to pre-existing condition or if premiums higher than those available through CHIP
  - http://www.chip.state.il.us/
Obtaining health insurance

- Medicare
  - On own record- If SSDI for 24 months, end stage renal disease, or ALS
  - On parent’s record- Childhood Disability Beneficiary- onset before 22; parent retires, becomes disabled, or dies- after receiving SSDI for 24 months can receive Medicare

- Medicaid
  - If meet SSI or SSDI disability determination, low-income and assets ($928/$2,000) or spend-down if higher income

- Health Benefits for Workers with Disabilities
  - Medicaid benefits for workers with disabilities with a higher income and assets ($3,159/$25,000)- can keep health care coverage by paying monthly premium
  - 1-800-226-0768
  - http://www.hbwdillinois.com/
Rewards of working with YSHCN

- Long term relationships and the opportunity to see maturation and progress
- Opportunities to learn about new problems
- Opportunities to use one’s cognitive and personal skills
- Really make a difference in the life of a patient
Contact us for more information or assistance

- Miriam Kalichman, MD
  DSCC
  312-996-7202
  mkalich@uic.edu

- Laura DeStigter, MPH
  ICAAP
  312-733-1026 x210
  ldestigter@illinoisaap.com