Progress and Challenges in Transitioning from Pediatric to Adult-Based Health Care Settings for People with Disabilities: A Local Perspective

Christopher Hanks M.D.
A Case (the patient’s perspective)

- A 23 year old female with cerebral palsy and has followed with the same pediatric provider for years. Her mother calls in to get a refill of her medications. She has been on the same medications for years. She is told that because of her age, she is too old to be seen at this clinic and needs to find a new provider to prescribe her medication.

  ▫ She is initially told they will not refill the medication. It is only after extensive discussion and argument that they agree to fill it for a 3 month supply.

  ▫ They are told no further refills will be provided and she will not be able to be seen again at that clinic because of her age.
A Case (the patient’s perspective)

• The patient’s mother asks their pediatrician if they have any recommendations for a new physician
  ▫ The pediatrician is unable to provide any recommendations

• The patient’s mother gets a list of accepted providers and calls several before finally finding one that they can get into before they run out of medications again.
A Case (the pediatrician’s perspective)

- The doctor gets a note from his office staff that his patient (a 23 year old female with CP) needs refill of her medications. The child has followed with him for about 10 years.

  ▪ The office has a policy that all patients older than 21 years old should switch to a new doctor. He discussed this with the family when she was 21 and encouraged them to find a new doctor.

  ▪ The doctor is “pretty sure” he reminded the patient’s mother of this policy again at her last appointment (age 22) so he tells his staff to tell the mom that he won’t refill them.

  ▪ After receiving multiple phone messages, he gives in, provides a 3 month refill

  ▪ He feels frustrated that he can’t help the patient more, but in his training, he never really cared for people over the age of 21, and he worries he might be missing important things that an “adult doctor” would know.
A Case (the adult-provider’s perspective)

• A new 23 year old patient with cerebral palsy comes to establish care with him. She is in a wheelchair and has significant spasticity and contractures of her arms and legs. She is quite thin

• His mom is very talkative, answering many questions even when he tries to ask them to the patient. The mother is very focused on getting refills, but is unsure of the doses of the medications.

• He asks about past surgeries or hospitalizations and is told she was in the NICU for 2 months as a newborn and has had a shunt ever since then. She has had surgeries and injections for her spasticity. She has a G-tube for feeds that they use “sometimes”. She used to get more services (PT/OT, etc) but lost a lot of these when she turned 21.

• Mom also mentions that she is almost due to be recertified for her disability and guardianship and “would you be able to fill out the paperwork for that?”

• Mom also wants to know if the doctor knows any good doctors to do botox injections for her contractures.
A case (the adult-provider’s perspective)

- The doctor informs mom he can’t refill medications until he has the doses but she can call back with those and he will refill them. He mentions he is not comfortable continuing to prescribe her baclofen, so will work on finding her a specialist for that.

- He has the mom fill out a records request form to send to the pediatrician.

- He asks them to return in 2-3 months for a “physical” (mom seems surprised by this, they have only seen their pediatrician once per year for many years unless she was sick).
The doctor requests records and gets...
Objectives

• Describe the current state of health care transition on a national and local level

• Discuss the challenges of the transition process for patients, families, and providers

• Discuss national efforts to improve provider’s ability to support the transition process.

• Discuss current local efforts being made to improve the transition process for people with chronic medical illness

• Describe future plans
What is health care transition?

• The Physician’s perspective:
  ▫ Transition is the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems”.
    • Blum et al. J Adol Health 1993;14: 570-576

• The Patient’s perspective:
  ▫ “Um just the move to be honest, I mean like, moving from like the kids’ bit to the adults’ bit is just like a big step, it’s like whoa.”
Health Care Transition - where are we now?

- **2002 consensus statement: AAP, AAFP, ACP**
  - Provided guidelines for transition process

- **2011:**
  - “After nearly a decade of effort, widespread implementation of health transition supports as a basic standard of high-quality care has not been realized.”

- **2014:** ???
The Changing Demographic of “Pediatric” Illness
The Changing Demographic of “Pediatric” Illness

- **Increasing prevalence:**
  - Autism: In children age 3-17, there was a 289% increase in autism from data collected in 1997-1999 compared to 2006-2008.
  - ADHD: In children age 3-17, there was a 33% increase in ADHD from data collected in 1997-1999 compared to 2006-2008.

The Changing Demographic of “Pediatric” Illness

- Increasing survival to adulthood:
  - How big of a population is this?

- 12.8% of children younger than 18 years have special health care needs
- 90% of these will live into adulthood
The Changing Demographic of “Pediatric” Illness

- Spina Bifida

The Changing Demographic of “Pediatric” Illness

- Complex congenital heart disease:
  - In 1950’s, only 20% of infants born with moderate or complex congenital heart disease survived their first year of life.
  - Now, 80-90% of these children live to adulthood.

Do patients have increased medical problems due to the lack of a smooth transition to adult care?

• During the transition period, there is evidence of:
  ▫ Increased hospitalizations
  ▫ Increased emergency room visits
  ▫ Increased frequency of exacerbation of illness
  ▫ Gaps of care
Patient/Family Transition Experience:

- This is not a new problem for parents:
  - Katherine Sangree Stokes, 1977
    - “Planning for the future of a severely handicapped autistic child.”

- “Now, despite years of struggle, it is clear that he, who will be socially dependent throughout his life, will further require that provisions be made for a sheltered living and working situation, for adequate financial support, and for a caring person to act as advocate for his needs. The discussion that follows is the fruit of years of thought, the kind that occupies parents in the long nights after their more immediate cares are set aside. This thought expresses itself in questions, not answers.”
What do patients/families think?

- Insurance issues
- Guardianship
- Housing
- Employability decreased for many
What do patients/families think?

• Life expectancy:
  • May have expectations of longer life than current estimates of life expectancy
    – Over 85% of patients with complex congenital heart disease expected to live longer than current estimates of their life expectancy.
  • Reid GJ et al. Estimates of Life Expectancy by Adolescents and Young Adults With Congenital Heart Disease. Journal of the American College of Cardiology 2006; 48: pp349-55
What do patients/families think?

- Leaving pediatric care is a logical step.
  - “I didn’t want to leave the trusted environment where everything is familiar and where you’re in charge. [...] Still, raising kids implies that you have to let them go and accept that they make their own choices. I didn’t like it that he had to go, but I saw the necessity. And now I see it’s good.”

- But...
  - “I’m just concerned about their personality...they might be like strict like concerned in a demanding way or something. I don’t like people who demand me to do anything I don’t want to do so maybe that’s why I haven’t [transitioned].”
    - Vijayan et al. *AIDS Care* 2009;21(10): 1222-1229
What do health care providers think?

• 1. National Data
• 2. Local Data
What do health care providers think?

- National data – 3 questions:
  1. Are there conditions that providers do not feel comfortable caring for?
     - If so, what are they?
  2. Is there a difference between the comfort level of trainees and established physicians?
  3. What are the barriers to physicians being more comfortable caring for these patients?
Proportion of PEDRs and IMRs who were comfortable with inpatient management of childhood-onset chronic disease.

- Asthma: PEDR (100%) vs. IMR (100%) (P = 1.00)
- Autism: PEDR (70%) vs. IMR (70%) (P < .001)
- Cerebral palsy: PEDR (50%) vs. IMR (50%) (P < .001)
- Congenital heart disease: PEDR (90%) vs. IMR (90%) (P = .02)
- Cystic fibrosis: PEDR (80%) vs. IMR (80%) (P < .001)
- Diabetes (type 1): PEDR (70%) vs. IMR (70%) (P = .008)
- Down syndrome: PEDR (90%) vs. IMR (90%) (P < .001)
- Epilepsy: PEDR (90%) vs. IMR (90%) (P < .001)
- Sickle cell disease: PEDR (80%) vs. IMR (80%) (P < .001)
- Spina bifida: PEDR (50%) vs. IMR (50%) (P = .001)

Patel M S, O'Hare K Pediatrics 2010;126:S190-S193
Proportion of PEDRs and IMRs who were comfortable with outpatient management of childhood-onset chronic disease.

Patel M S, O'Hare K Pediatrics 2010;126:S190-S193
Proportion of PEDRs and IMRs who were likely to care for patients with specified childhood-onset chronic disease after the completion of residency.

Patel M S, O'Hare K Pediatrics 2010;126:S190-S193
Internal Medicine Residents and transition of patients...

- 220 surveys distributed to residents
  - 64 Internal Medicine residents responded
  - 30 Pediatrics residents responded
  - Have they participated in an educational session dedicated to transition?
    - 13.8% of Internal Medicine residents
    - 73% of Pediatrics residents

Patel M S, O'Hare K Pediatrics 2010;126:S190-S193
What about adult primary care providers?

Survey of Adult Health Care Providers about Health Care Transition for Youth with Special Health Care Needs. Special Medical Services of New Hampshires DHHS, 2008.
Internists and transitioning patients

• Survey of 67 randomly selected Internists:
  ▫ “Please list concerns you have about accepting the care of medically complex patients as they transition from child-centered care to adult-centered medical care.”
  • 3 items cited by greater than 5 participants:
    • 1. Difficulty obtaining records  System Problem
    • 2. Lack of training in pediatric onset and congenital disorders. Education/Training Problem
    • 3. Parents often being reluctant to relinquish responsibility for healthcare/decision-making to young adult patients  Culture Problem

What do health care providers think?

- Local Data
  - Pediatricians:
  - Adult-care Providers:
Needs Assessment of Pediatric Providers
What is your specialty or area of practice?

- General Pediatrics
- Gastroenterology
- Allergy/Immunology
- Pulmonary
- Developmental/Behavioral
- Neonatal
- Heme/Onc
- Emergency Medicine
- Endocrinology
- Nephrology
- Neurology
- Adolescent
- Pediatric Intensive Care
- Toxicology
- Cardiology
- Palliative Medicine
- Sports Medicine
- Neurodevelopmental
- Infectious Disease
- Neuropsych
How many patients between the age of 16-25 do you care for?

<table>
<thead>
<tr>
<th>Range</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>0-20</td>
<td>8.3%</td>
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<tr>
<td>20-50</td>
<td>33.3%</td>
</tr>
<tr>
<td>50-100</td>
<td>21.7%</td>
</tr>
<tr>
<td>100-200</td>
<td>16.7%</td>
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<tr>
<td>200-300</td>
<td>10.0%</td>
</tr>
<tr>
<td>More than 300</td>
<td>10.0%</td>
</tr>
</tbody>
</table>
Of the patients you care for between 16-25, what percentage of them have chronic medical conditions?

- 0-20%: 11.4%
- 21-40%: 27.1%
- 41-60%: 14.3%
- 61-80%: 10.0%
- 81-100%: 37.1%
Does your practice currently have a policy for preparing patients to transition to adult-care providers?

- No: 72.9%
- Yes: 27.1%
At what age do you typically discuss or begin to plan for transition of care to adult-care providers?

- 11-13 years old: 5.9%
- 14-15 years old: 11.8%
- 16-17 years old: 16.2%
- 18-19 years old: 30.9%
- 20 years old or older: 16.2%
- I do not discuss this with my patients: 19.1%
How often do your patients have difficulty successfully establishing care with the necessary adult providers?

- More than 75% of the time: 23.6%
- Between 50-75% of the time: 16.4%
- Between 25-50% of the time: 14.5%
- Less than 25% of the time: 45.5%
Which of the following result in a significant barrier to successful transition to adult-care providers for you and your patients? (mark all that apply).

- Preparing my patients for successful transition is too time-consuming (11.9%)
- Adult providers are not educated or not comfortable enough in the care of the diseases my patients are being treated for (37.3%)
- I don't know the adult providers in my area well enough (37.3%)
- I have difficulty letting go of the care of my patients due to the prolonged relationship I have with them (6.8%)
- The parents/guardians of my patients are resistant to transfer out of my care (61.0%)
- My patients are resistant to transfer out of my care (61.0%)
- I/My patients have difficulty identifying adult providers willing to accept the transfer of my patients to them (54.2%)
Needs Assessment of Adult Providers
What is your specialty or area of practice?

- General Internal Medicine: 9
- Family Medicine: 9
- General Internal Medicine/Pediatrics: 3
- Internal Medicine Subspecialty: 23
- Subspecialty Neurology: 4
- General Neurology: 0
- Subspecialty Internal Medicine...: 6
- Dermatology: 1
How many patients between the age of 16-25 do you provide ongoing care for as either a subspecialist or primary care provider?
Of the patients you care for between age 16-25, what percentage of them have chronic medical conditions that started in childhood? (Examples include Juvenile onset diabetes, cerebral palsy, spina bifida, autism, congenital heart disease, sickle cell anemia, etc)

<table>
<thead>
<tr>
<th>Percentage Range</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>0-20%</td>
<td>57.10%</td>
</tr>
<tr>
<td>21-40%</td>
<td>8.90%</td>
</tr>
<tr>
<td>41-60%</td>
<td>8.90%</td>
</tr>
<tr>
<td>61-80%</td>
<td>5.40%</td>
</tr>
<tr>
<td>81-100%</td>
<td>19.60%</td>
</tr>
</tbody>
</table>
At what age would you typically want a patient with chronic illness who has been followed by a pediatrician or pediatric subspecialist to be transferred to your care?

- Younger than 16 years old: 3.7%
- 16-17 years old: 16.7%
- 18-19 years old: 40.7%
- 20-22 years old: 25.9%
- 23-25 years old: 9.3%
- 26 years old or older: 3.7%
How often do you receive direct communication (written or verbal) from a patient’s pediatric provider before they are transferred to your care?

- More than 80% of the time: 11%
- Between 61-80% of the time: 5%
- Between 41-60% of the time: 4%
- Between 21-40% of the time: 5%
- Less than 20% of the time: 75%
How often do you have difficulty obtaining medical records on patients transferred to you from pediatric providers?

- More than 80% of the time: 16.7%
- Between 61-80% of the time: 7.4%
- Between 41-60% of the time: 13.0%
- Between 21-40% of the time: 24.1%
- Less than 20% of the time: 38.9%
When you receive medical records for patients transferred to you from pediatric providers, how often do you have the following problems? (Mark all that apply)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Less than 20% of the time</th>
<th>Between 21-40% of the time</th>
<th>Between 41-60% of the time</th>
<th>Between 61-80% of the time</th>
<th>More than 80% of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too many records are sent</td>
<td>61.7% (29)</td>
<td>4.3% (2)</td>
<td>17.0% (8)</td>
<td>12.8% (6)</td>
<td>6.4% (3)</td>
</tr>
<tr>
<td>Records are illegible</td>
<td>58.0% (29)</td>
<td>14.0% (7)</td>
<td>14.0% (7)</td>
<td>10.0% (5)</td>
<td>4.0% (2)</td>
</tr>
<tr>
<td>Too few records are sent</td>
<td>44.0% (22)</td>
<td>14.0% (7)</td>
<td>14.0% (7)</td>
<td>10.0% (10)</td>
<td>8.0% (4)</td>
</tr>
<tr>
<td>Records are difficult to follow</td>
<td>40.0% (20)</td>
<td>14.0% (7)</td>
<td>12.0% (6)</td>
<td>22.0% (11)</td>
<td>12.0% (6)</td>
</tr>
</tbody>
</table>
What is/are the largest barrier(s) to successful transfer of patients from pediatric providers to your care? (Select all that apply)

- I do not have the necessary support from ancillary staff in my clinic to care for these patients (19.2%)
- The patients have expectations that are not realistic for me to meet (26.9%)
- I do not receive adequate records from the previous providers (51.9%)
- Patients and their family do not know enough about their medical history (40.4%)
- Lack of knowledge and/or training in the care of the patients' condition (23.1%)
What can be done???
What can be done? A local example...

• **From 1999-2006:**
  ▫ All rheumatology patients at NCH age 16 and older
  ▫ Offered transition services.
    • Provided by a grant-funded social worker
      • Assess current knowledge of transition
      • Establish written goals.
      • Transition education packet proved to each family
      • Individualized transition plan established
    • Social worker met with families at subsequent visits and helped coordinate ultimate transfer to an adult rheumatology provider.
    • Patients who were eligible for transition services but did not meet with social workers were used as controls.
  ▫ Successful transition defined as a patient being regularly followed by an adult provider 6-8 months after initial appointment.

Unpublished data from Paul Jensen, Jill Karnes, Karla Jones, Amy Lehman, Robert Rennebohm, Gloria Higgins, and Stacy Ardoin.
A local example...

- 210 agreed to participate in the transition program.
  - 89 (42%) had successful transition
  - 49 (23%) did not have successful transition
  - 39 (19%) lost to follow-up
  - 33 (16%) were still followed by NCH rheumatologists (all under age 21).

- 26 patients “eligible” for transition program but did not receive transition services.
  - 6 (23%) had successful transition
  - 15 (58%) did not have successful transition

Unpublished data from Paul Jensen, Jill Karnes, Karla Jones, Amy Lehman, Robert Rennebohm, Gloria Higins, and Stacy Ardoin.
Current national efforts

- Gottransition.org
- MCHB Core outcome
- Health Care Transitions Research Consortium
- SGIM Adults with Complex Conditions Originating in Childhood Task Force
- PAS Health Care Transition and Self Management Special Interest Group
- Many others...
Current local efforts:

• Many small groups working on transitional care
  ▫ Most are specialists
  ▫ In the pediatric setting, specialists are much more likely to perform “primary care”-type roles than in the adult setting

• These patients need improved support in primary care as well
Current local efforts:

• The Center for Autism Services and Transition (CAST)
  ▫ Opened in March 2014
  ▫ Based in Hilliard, OH
Services offered: CAST

**Medical Home Model**
- **Age 15 and up**
  - Establish with CAST team as PCP and continue with them for life

**Consultative Bridge Model**
- **Age 15 and up**
  - Begin consultative visits with CAST team
  - Establish with a non-pediatric PCP and continue with them
- **Age 18 and up**
  - Transition to other specialists as needed
- **Age 18 and up**
  - Transition to other specialists as needed

End CAST visits once well established with new providers.
CAST

- Why not provide ongoing primary care for all disabled populations?
  - Volume/Sustainability
  - Distance
  - Allows us to support pediatric providers in preparing for transition
  - Allows us to support adult providers in knowing what to plan for and for those not well prepared at the time of transfer of care.
Services offered: CAST

• Referrals from adult-care providers will also be accepted
  ▫ Goal of creating a “plan from here” that the new providers can follow and feel comfortable managing the patient.
Output of consultative model

- Transition Plan
- Portable Medical Summary
- Medical “passport”
- Care coordination
- Short-term primary care if needed
CAST

• Current interventions:
  ▫ Pre-visit assessment
  ▫ Willing to provide alternate visit arrangements
  ▫ Transition Readiness Assessments
  ▫ Care Coordination:
  ▫ Timing of transition:
    • Ideally not transition for primary care and specialists at the same time
      • Establish with CAST 1st
      • Over time (1-2 years) transition to other providers as needed.

• Coming soon...
  ▫ Social worker
  ▫ Clinical pharmacist (for medication management support and consultation)
  ▫ More physicians

• What else?
CAST: What have we learned so far?

- Things patients have needed so far:
  - Dental
  - Gynecologic care
  - Lab work
  - Nutrition support
  - A diagnostic work-up
  - Connect with local Board of DD for services
  - Guardianship
  - Crisis intervention
  - Medication refills
  - Care coordination with other providers
  - Clarification of prescriptions with pharmacist
  - Help finding resources

- And...a primary care provider that understands them!
Back to the case of the 23 year old with cerebral palsy...
Challenges and next steps for pediatricians:

- **Pediatricians challenges/needs:**
  - A transition plan
  - Starting early
  - Time to prepare patients for the transition
  - Knowledge of who to send their patients to.
  - Developing a “plan for the future provider to follow”

- **Next steps:**
  - Education on developing a transition plan
  - Development and utilization of resources for pediatricians to use to help them prepare patients/families.
  - Support for preparing complex patients for transition.
Challenges and next steps for Adult-care providers

- **Adult Care Providers’ challenges/needs:**
  - Knowledge about the care of conditions that originate in childhood that persist into adulthood
  - Obtaining records
  - “The plan from here…”
  - Patients lack of knowledge and/or self-advocacy
  - Patient expectations are “not realistic”

- **Next steps:**
  - **Education**
    - Medical Students
    - Residents
    - Practicing physicians
  - Support for management of patients that have transferred to them to identify current and future needs and how to address them.
    - Portable medical summary for patients
  - Patient education
  - Improved access to necessary specialists
Challenges and next steps for patients and their families

- **Challenges/needs:**
  - Early preparation
  - Knowledge of own medical conditions
  - Development of skills
  - Leaving the known for the unknown
  - Culture change
  - Less direct specialty care

- **Next steps:**
  - Transition readiness assessments
  - Transition plans
  - Portable Medical Summary
  - Maximize autonomy in medical care.
  - Improved/alternate methods for access to medical care to accommodate disability
    - Electronic communication
    - Alternative visit formats
Questions?

- Thank you to the following people who have helped with the collection of information, development of CAST, or other efforts that have made this possible:
  - Bill and Marci Ingram
  - Michael Grever
  - Wael Jarjour
  - Kim Bates
  - Stacy Ardoin
  - Karen Ratliff-Schaub
  - Clay Marsh