Bridging the Gap Between Pediatric and Adult Subspecialty Care: Development of a Cardiac Transitions Program

Kimberly McHugh
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musc Children's Health
Medical University of South Carolina
Changing What's Possible

Disclosures

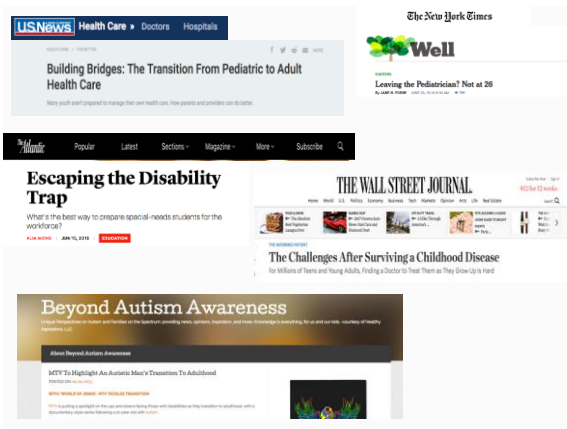
- No relevant financial relationships or interests

Objectives

- Describe the "Got Transition" *Six Core Elements* of Health Care Transition
- Overview 3 areas of pilot transition processes at MUSC
- Discuss the next steps of advancing transitional care at MUSC

Guidelines and Policy Statements

- 2007 AAP Annual Leadership Forum
  - designated "transitioning youth with special health care needs to adult health care" as a top-10 priority
- *Bright Futures*
  - encourages parental support of self-management and independent decision-making about health
- Healthy People 2020
  - Increase the proportion of youth with SHCN whose healthcare provider discussed transition planning
- Maternal and Child Health Bureau
  - Youth with SHCN should receive coordinated comprehensive care within a medical home and all services necessary to make the transitions to all aspects of adult life
- AAP, ACP, AAFP Clinical Report on Health Care Transitions
  - Published in 2011, update from 2002 consensus statement
- American College of Physicians
  - *Pediatric to Adult Care Transition Initiative*



Got Transition?

- National Alliance to Advance Adolescent Health
  - Funded by HRSA/MCHB
- www.gottransition.org

got transition?
NATIONAL HEALTH CARE TRANSITION CENTER

Why Six Core Elements?

- Address barriers to transition
  - Lack of planning
    - Families/providers unprepared; staff unprepared; adolescents unengaged and unprepared
  - Adult providers unprepared…
    - …and receive limited information
- Address issues within all primary care fields
- Lack of appropriate tools

Six Core Elements

1. Transition Policy

- Describe practice's approach to transition
  - Privacy and consent
  - Explicitly state age at which youth shift from pediatric to adult model of care
- Implementation:
  - Educate staff about policy
  - Post policy and share with patients/families (beginning at age 12-14)

got transition | Sample Transition Policy
Six Core Elements of Health Care Transition 2.0

[*Pediatric Practice Name*] is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a "pediatric" model of care where parents make most decisions to an "adult" model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

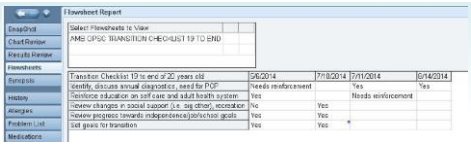
At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult's consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

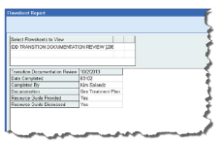
We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.

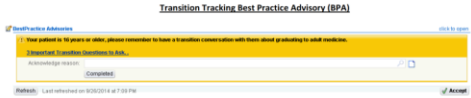
2. Transition Tracking and Monitoring

- Establish criteria and process for identifying transitioning youth and create registry
- Utilize flow sheet to track transition progress
- Incorporate Six Core Elements into clinical care process, utilizing EHR



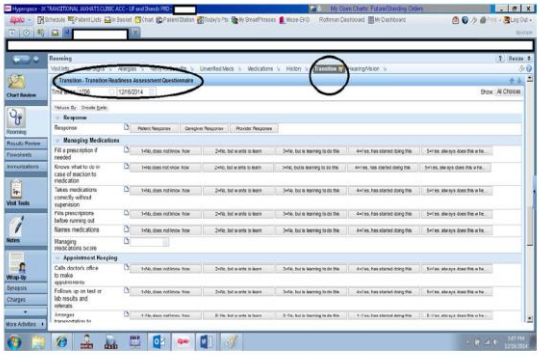


Transition Tracking Best Practice Advisory (BPA)



3. Transition Readiness

- Conduct regular transition readiness assessments
  - Begin at age 14
  - Discuss with youth and family
  - Can bill for completion
- Jointly develop goals and actions with youth and caregiver
  - Document regularly



4. Transition Planning

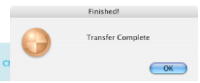
- Regularly update plan of care
  - Readiness assessments
  - Medical summary and emergency plan
  - Condition fact sheet
- Prepare patient/family for adult approach to care at age 18
  - Legal changes/decision-making support
  - Self-advocacy
  - Access to information
- Plan for optimal timing of transfer (primary and specialty)
- Obtain consent for release of medical information
- Identify adult provider(s) and communicate plan of care
- Provide resources (insurance, commu supports)

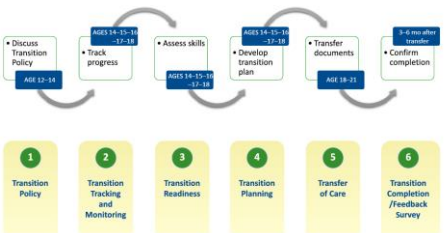
5. Transfer of Care

- Confirm date of first adult provider appointment and provide DIRECT COMMUNICATION with adult provider
- Complete and send transfer packet
  - Final readiness assessment
  - Plan of care with transition goals and pending actions
  - Medical summary and emergency plan
  - Legal documents
  - Condition fact sheet
- Prepare letter to send with packet and confirm sent
- Plan for continued responsibility of care until first adult appointment

6. Transfer Completion

- Contact young adult/caregiver 3-6 months after last pediatric appointment to confirm transfer of responsibilities to adult provider
- Elicit feedback on transition process
- Communicate with adult provider and offer consultation assistance
- Build continued partnerships with adult primary and specialty care providers





Do they work?

- 2 year learning collaborative
  - 5 large academic primary care practices in DC
    - Adolescent, pediatrics, family medicine, internal medicine
  - Patients age 14-24 years
  - Insured by Medicaid
- Participated in 5 1.5 day learning sessions; regular "coaching sessions", on-site visits

Do they work?

- Assessed progress on each core element on scale of 1 (basic)-8 (comprehensive)
  - Nearly all sites were at a basic level at start (scores 1-2)
  - At 15 months all scores neared or exceeded 5
    - Lowest score for Transition Planning

Is it feasible?

- Six core elements and sample tools made the proc possible
- Has to be team-based, not just physicians
- Unable to incorporate assessment tools into EHR
- Care plans and transfer summaries were time-consuming
- The earlier the process started, the better
  - Older adolescents need an "accelerated" process
- Over time the importance of the role of adult providers became more clear

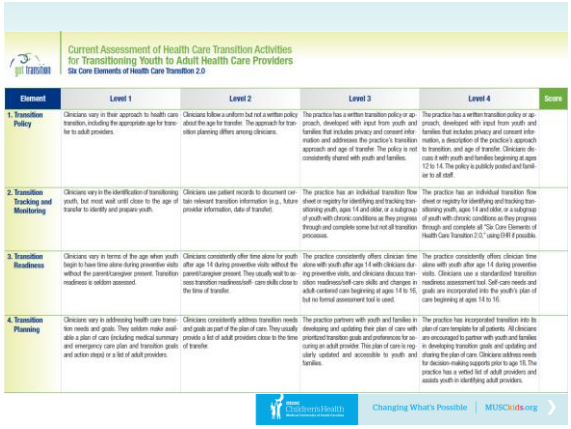
Is it feasible?

- Challenges
  - Compensation for time
  - Lack of EHR functionality for transitions
  - Lack of care coordination infrastructure
    - (particularly for adult sites)
- What works best
  - Start with a clearly defined population
  - Transfer with up to date medical summary and one-page information sheet about pediatric illness; clarify guardianship/decision-making before transfer; pediatric provider available for consultation
  - Start with a mix of ages
  - Sufficient care coordination is available

MUSC Transition Pilots

MUSC Transition Pilots

- 3 self-selected pilot sites
- Advance progress through Six Core Elements
- Monthly assessments and goal setting
- Determining/tracking outcome measures



Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers
Six Core Elements of Health Care Transition 2.0

Element	Level 1	Level 2	Level 3	Level 4	Score
1. Transition Policy	Clinicians vary in their approach to health care transition, including the appropriate age for transfer to adult providers.	Clinicians follow a uniform but not a written policy about the age for transfer. The approach for transition planning differs among clinicians.	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information and addresses the practice's transition approach and age of transfer. The policy is not consistently shared with youth and families.	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice's approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12 to 14. The policy is publicly posted and familiar to all staff.	
2. Transition Tracking and Monitoring	Clinicians vary in the identification of transitioning youth, but most wait until close to the age of transfer to identify and prepare youth.	Clinicians use patient records to document certain relevant transition information (e.g., future provider information, date of transfer).	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete some but not all transition processes.	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete all "Six Core Elements of Health Care Transition 2.0," using EHR if possible.	
3. Transition Readiness	Clinicians vary in terms of the age when youth begin to have time alone during preventive visits without the parent/caregiver present. Transition readiness is seldom assessed.	Clinicians consistently offer time alone for youth after age 14 during preventive visits without the parent/caregiver present. They usually wait to assess transition readiness/self- care skills close to the time of transfer.	The practice consistently offers clinician time alone with youth after age 14 with clinicians during preventive visits, and clinicians discuss transition readiness/self-care skills and changes in adult-centered care beginning at ages 14 to 16, but no formal assessment tool is used.	The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool. Self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14 to 16.	
4. Transition Planning	Clinicians vary in addressing health care transition needs and goals. They seldom make available a plan of care (including medical summary and emergency care plan and transition goals and action steps) or a list of adult providers.	Clinicians consistently address transition needs and goals as part of the plan of care. They usually provide a list of adult providers close to the time of transfer.	The practice partners with youth and families in developing and updating their plan of care with prioritized transition goals and preferences for securing an adult provider. This plan of care is regularly updated and accessible to youth and families.	The practice has incorporated transition into its plan of care template for all patients. All clinicians are encouraged to partner with youth and families in developing transition goals and updating and sharing the plan of care. Clinicians address needs for decision-making supports prior to age 18. The practice has a vetted list of adult providers and assists youth in identifying adult providers.	

Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers (continued)
Six Core Elements of Health Care Transition 2.0

Element	Level 1	Level 2	Level 3	Level 4	Score
5. Transfer of Care	Clinicians usually send medical records to adult providers in response to transitioning patient requests.	Clinicians consistently send medical records to adult providers for their transitioning patients.	The practice sends a transfer package that includes the plan of care (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet).	The practice sends a complete transfer package (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet), and pediatric clinicians communicate with adult clinicians, confirming pediatric provider's responsibility for care until young adult is seen in the adult practice.	
6. Transfer Completion	Clinicians have no formal process for follow-up with patients who have transferred to new adult providers.	Clinicians encourage patients to let them know whether or not the transfer to new adult provider went smoothly.	The pediatric practice communicates with the adult practice confirming completion of transfer/first appointment and offering consultation assistance, if needed.	The practice confirms transfer completion, need for consultation assistance, and elicits feedback from patients regarding the transition experience.	
Youth and Family Feedback	The practice has no formal process to obtain feedback from youth and families about transition support.	The practice obtains feedback from youth and families using a transition survey.	The practice involves youth and families in developing or reviewing the transition survey and conducts the survey with eligible youth and families.	The practice involves youth and families in developing or reviewing the transition survey, conducts the survey with eligible youth and families, and involves youth and families in developing strategies to address areas of concern identified by the transition survey.	
Youth and Family Leadership	Clinicians provide youth and families with tools and information about health care transition.	The practice involves youth and families in creating and implementing education programs for practice staff related to transition.	The practice includes youth and families as active members of a youth advisory council for transition or a transition quality improvement team.	The practice ensures equal representation of youth and families in strategic planning related to health care transition.	

The table at right can be used to total the number of points that your practice obtained on the pediatric version of the Current Assessment of Health Care Transition Activities.

This form is being completed to asses:

- An Individual Provider
- An Individual Practice
- A Practice Network

Transition Activities	Possible	Score
Transition Policy	4	
Tracking and Monitoring	4	
Transition Readiness	4	
Transition Planning	4	
Transfer of Care	4	
Transfer Completion	4	
Youth and Family Feedback	4	
Youth and Family Leadership	4	
Total	32	

Congenital Heart Disease

- Monthly Transition clinic
  - Age 11 and up (currently mostly older patients)
- Providers
  - Kim McHugh MD, Rochelle Judd FNP
    - Stephanie Gaydos MD
  - SW, PharmD
- Initial Assessment Score: 15/32

Congenital Heart Disease

- Transition Policy
  - Formalized and implemented
  - Adult clinic welcome letter
- Transition Tracking and Monitoring
  - Established patient list in Epic for tracking
- Transition Readiness
  - Using TRAQ and PedsQoL

Congenital Heart Disease

- Transition Planning
  - Completing readiness assessments
  - Adult provider identified; adult NP addresses issues such as reproduction
- Transfer of Care
  - No set criteria
  - Trying to move older patients along
- Transfer Completion
  - Continued conversations between adult and pediatric teams
- Follow up Assessment Score: 21/32

Rheumatology

- Building a transition clinic/services
- Currently have a multidisciplinary Lupus clinic
  - Patients seen q3mo
- Providers: Natasha Ruth MD, Katherine Silver MD
  - Sonia Savani MD
- Initial Assessment Score: 11/32

Rheumatology

- Transition Policy
  - Drafted and beginning implementation
  - Working on adult welcome letter
- Transition Tracking and Monitoring
- Transition Readiness
  - Plan to use TRAQ

Rheumatology

- Transition Planning
  - Medical summary and plan of care form developed
  - Condition fact sheets established
    - https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative
  - MUSC adult providers identified
- Transfer of Care
  - Transfer letter developed
- Transfer Completion
  - Continued communication between adult and pediatric providers (when transitioning in MUSC system)
- Follow up Assessment Score: 17/32

Inflammatory Bowel Disease

- Transition Clinic
  - Q3 months
  - Patients enter at age 17; exit after 2-3 visits
- Providers: Christine Carter-Kent MD, Jennifer Seminerio-Diehl
  - SW, CM, RD
- Initial Assessment Score: 16/32


Inflammatory Bowel Disease

- Transition Policy
  - Drafted and implemented
  - Working on adult welcome letter
- Transition Tracking and Monitoring
  - Developing Epic list of patients
- Transition Readiness
  - Using internal scale adapted from validated scale developed at UNC

Inflammatory Bowel Disease

- Transition Planning
  - Readiness assessments being performed
  - Medical summary and plan of care in place
  - Patients given information on local adult providers
- Transfer of Care
  - No set criteria
- Transition Completion
  - MUSC adult providers considering becoming "hub" to assist with complex patients
- Follow up Assessment Score: 22/32

Challenges/Next Steps

- If transition clinic in place, addressing all patients not enrolled
- Engaging all faculty to participate
- Engaging patients/families to review material
- Utilizing Epic capabilities
- Measuring outcomes
- Can I get paid for this?!?

Billing/Coding Tips

- No billing codes available specifically for transition services
- Available codes:
  - Care Plan Oversight Services (CPT 99339)
  - Prolonged services by time
  - Interprofessional Telephone/Internet Consultations (CPT 99446)
  - Health Risk Assessment (CPT 96160-patient; 96161-caregiver)

Where can you start?

- Begin talking to your patients about self-management and transition at age 12-14
- Meet with colleagues to discuss the development of a transition policy for your area
- Implement a transition readiness assessment tool
- Directly contact adult colleagues prior to transfer of care
  - Consider introducing patient to adult provider before transfer if feasible
- Utilize an "adult model of care" if seen past age 18yo
- Contact me☺

Other Considerations

- This is not just a "pediatrician problem"
  - i.e. what about those adult doctors?
- Use of patient-centered technology (personally-controlled health records) can support patients and families during transition
- AAP has developed MOC modules around transitions of care
- Coordination between many providers
  - Collaborative; initiated by clinicians managing the main health issue or through PCP

Future Directions

- Formalize transitions of care from PPC to UIM
- Incorporate more specialty care sites
- Standardize checklists and transfer packet components
  - Utilize EMR resources
- Engage adult providers
- Engage patients and families
- Engage the community

Acknowledgements

- Sarah Mennito

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Questions?