Transition of care for youth with special health care needs

Lisa Tuchman , MD, MPH
Children's National Health System
Children's Research Institute/Center for Translational Science
Division of Adolescent and Young Adult Medicine
Washington, DC

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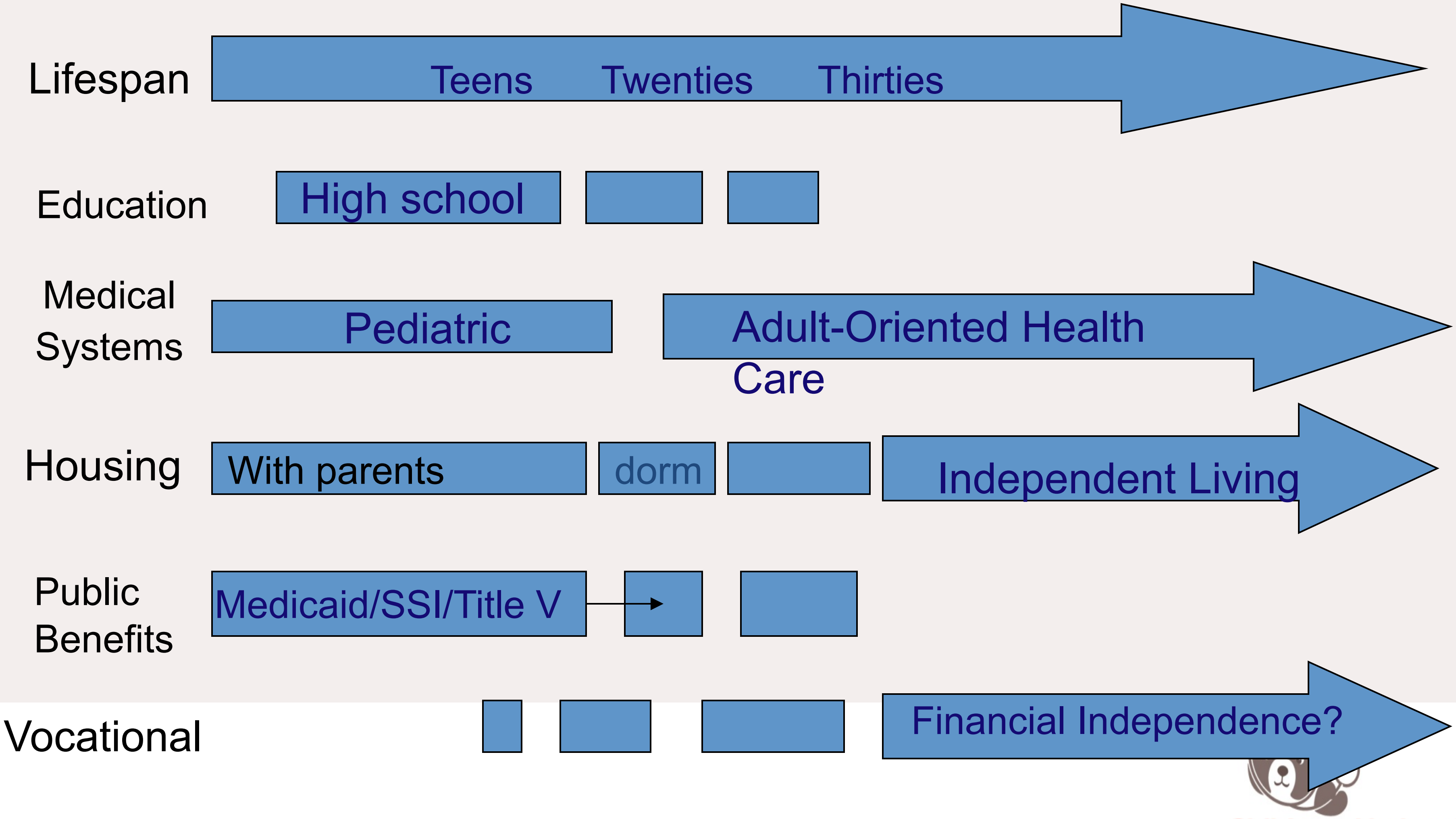
Adolescents and Young Adults with Chronic Health Conditions

- Estimated that over 30% of adolescents have at least one chronic condition in the US
- 33% of those are moderate/severe
- 90% of children with chronic conditions live beyond age 20 years
- Significant gains in life expectancy beyond childhood in recent decades (e.g., Cystic Fibrosis, Sickle Cell, Cancer, Congenital Heart Disease, Spina Bifida, HIV, Trisomy 21,etc.)
- Will inevitably need adult-based care that is developmentally and medically appropriate.
- Transition from pediatric to adult medical care is a high-risk period for morbidity and mortality

Transitions During Young Adulthood



Lifespan: Teens, Twenties, Thirties

Education: High school

Medical Systems: Pediatric, Adult-Oriented Health Care

Housing: With parents, dorm, Independent Living

Public Benefits: Medicaid/SSI/Title V

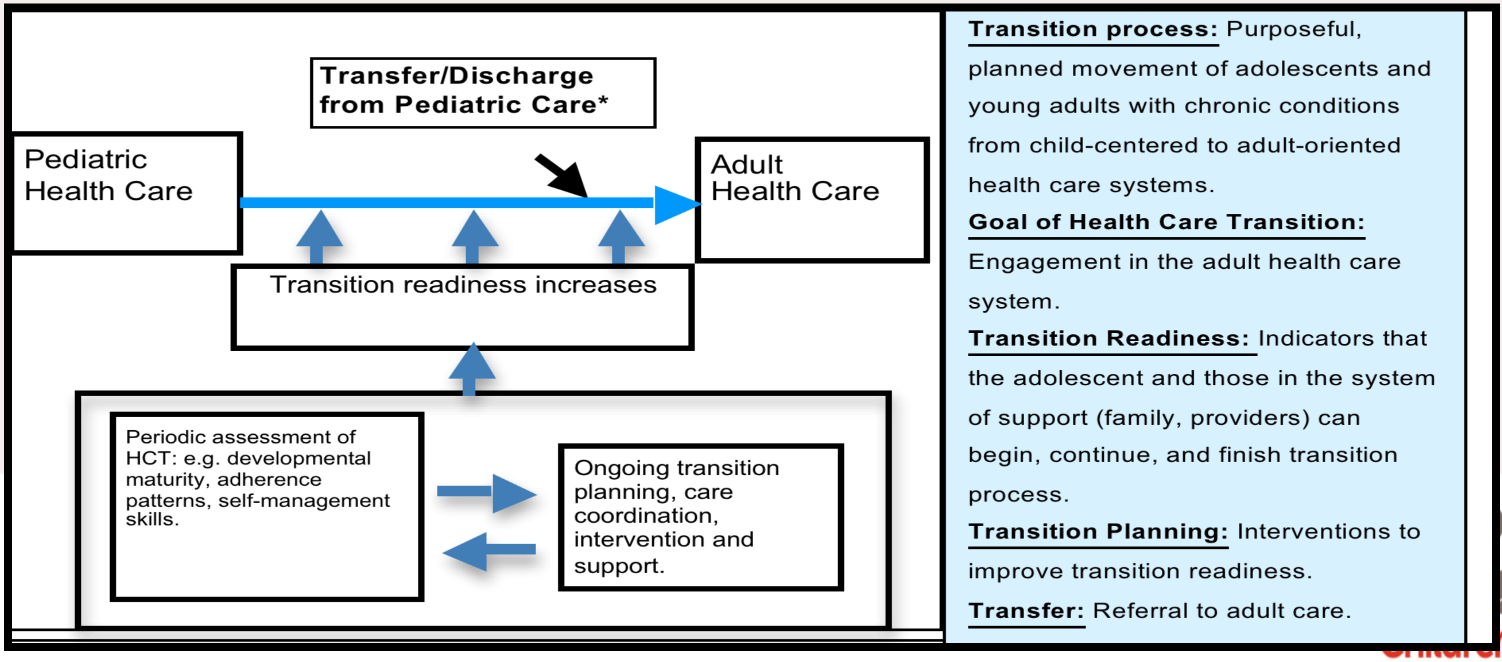
Vocational: Financial Independence?

2011 Clinical Report on Transition

AAP, AAFP, and ACP joint report

6 core recommendations for HCT programs within medical home

- Practice-based components (i.e. written transition policy, transitioning youth registry, and transfer of care)
- Patient-level components (i.e. transition planning and completion)



Transfer/Discharge from Pediatric Care*

Pediatric Health Care

Adult Health Care

Transition readiness increases

Periodic assessment of HCT: e.g. developmental maturity, adherence patterns, self-management skills.

Ongoing transition planning, care coordination, intervention and support.

Transition process: Purposeful, planned movement of adolescents and young adults with chronic conditions from child-centered to adult-oriented health care systems.

Goal of Health Care Transition: Engagement in the adult health care system.

Transition Readiness: Indicators that the adolescent and those in the system of support (family, providers) can begin, continue, and finish transition process.

Transition Planning: Interventions to improve transition readiness.

Transfer: Referral to adult care.

Differences between systems/models of care

	Pediatric	Adult
Age-related	Growth, development and future focused	Maintenance/ decline; optimize the present
Focus	Family	Individual
Approach	Proactive, paternalistic	Reactive, collaborative
Shared decision-making	With family/ parent	With patient who is a self-advocate
Insurance/ services	Entitlement	Qualify/eligible
Non-adherence	More assistance	More tolerance
Procedural Pain	Lower threshold	Higher threshold
# of patients	Fewer	Greater

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Consequences of Poor Transition

- Gaps in or loss of health insurance
- Gaps in care: no identified adult medical home
- Utilization of costly emergency medical services that are potentially preventable
- High-risk period for morbidity and mortality (e.g., worse glycemic control in diabetes, graft failure in transplant patients, worsening late effects in cancer survivors)
  - Transition-related morbidities even greater for minority and low-income youth
- Prevent new pediatric patients from entering the system.

Lotstein et al (2008); Gurvitz et al. (2007); Broussequ et al. (2010); Quinn et al. (2010); Gilliam et al. (2011); Stanto & Rutherford (2005); Lotstein et al. (2010); Ngui & Flores (2007)'; Crowley et al. (2011)

What to do? Where to start?

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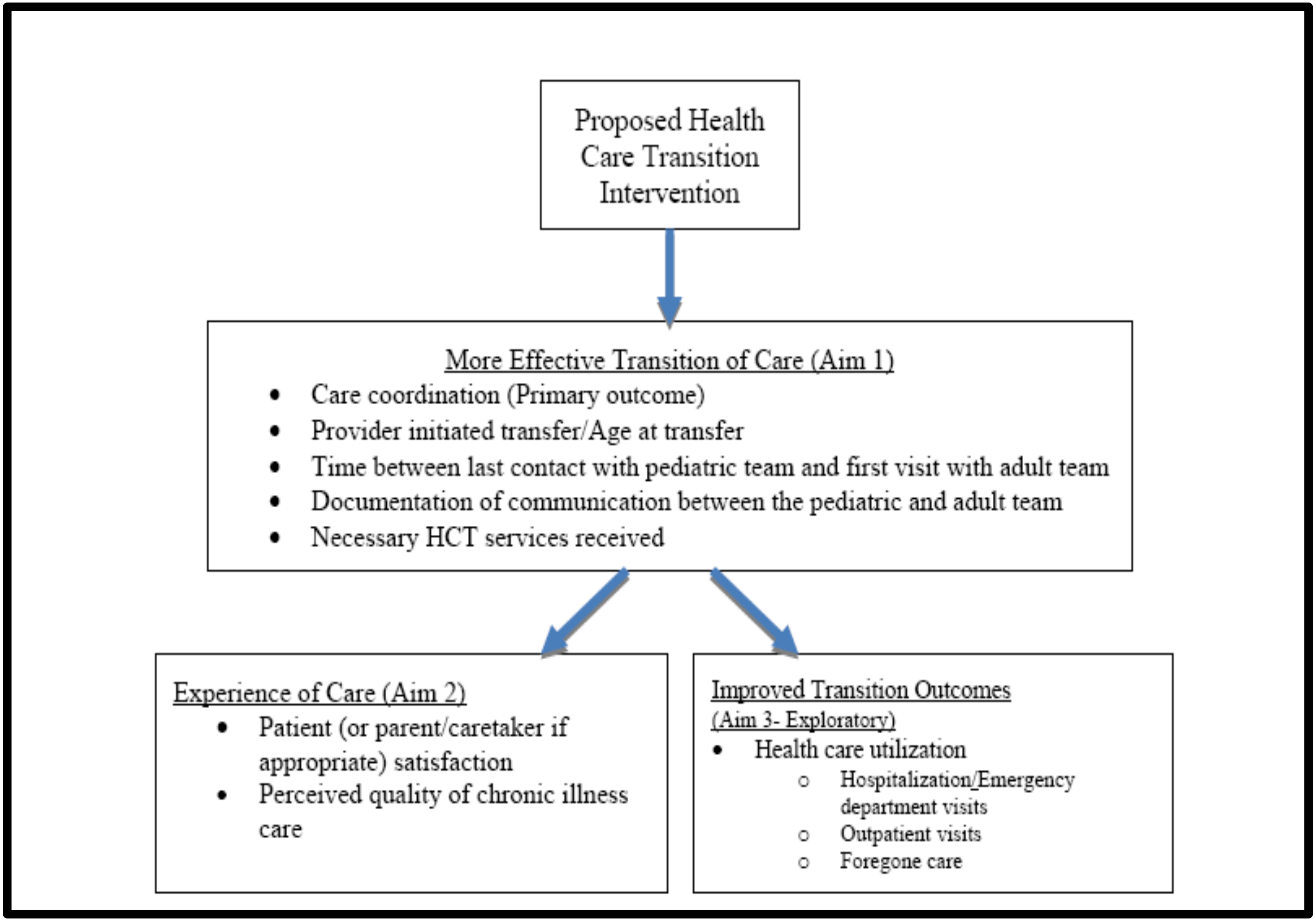
Expert consensus = better outcomes?

- While these are important guidelines and best practices, evidence has been slow to evolve around impact these practices have on experience, health outcomes, and cost (Triple Aim)[1]
- Proof of effectiveness of these recommendations has not been determined.
- Evaluate outcomes associated with MCHB NS CSHCN Questions (have never been evaluated)
- The Agency for Healthcare Research and Quality (AHRQ) recently published a technical brief reporting a lack of rigorous research evaluating the comparative effectiveness of HCT interventions for youth with special needs.[2]

[1] Prior M, McManus M, White P, Davidson L. Measuring the "Triple Aim" in Transition Care: A Systematic Review. Pediatrics 2014;134;e1648.

[2] Agency for Healthcare Research and Quality. Evidence-based Practice Center Technical Brief Protocol: Transitions of Care for Children with Special Health Care Needs. Rockville, MD: AHRQ; Oct 2013


Proposed Health Care Transition Intervention
More Effective Transition of Care (Aim 1)
Care coordination (Primary outcome)
Provider initiated transfer/Age at transfer
Time between last contact with pediatric team and first visit with adult team
Documentation of communication between the pediatric and adult team
Necessary HCT services received
Experience of Care (Aim 2)
Patient (or parent/caretaker if appropriate) satisfaction
Perceived quality of chronic illness care
Improved Transition Outcomes
(Aim 3- Exploratory)
Health care utilization
Hospitalization/Emergency department visits
Outpatient visits
Foregone care

Methods

Setting: Adolescent Health Center at Children’s National

Active participants (N = 210)
Enrolled over a 1.5 year period: June 2012-December 2013

Inclusion criteria

- 16-22 year old adolescents with special health care needs
- Insured by DC HSCSN
- Half received usual care enhanced by written transition information
- Half received a health care transition intervention modeled on the AAP/AAFP/ACP best practices report
- Random Assignment
- Assessed via interviews, standardized outcome measures, insurance data (baseline, 6, 12, 18, 24 months)

Participant characteristics

- 210 patients ages 16-22 years old (mean age 18.9 +/-1.7 years) enrolled
- 100% insured by HSCSN
- 105 participants were randomized to the HCT care coordination intervention group, and the other 105 were randomized to the control group.
- Patients were stratified as low, medium, or high care coordination tier at baseline using a standardized instrument.
- 100.0% self identify as AA
- 65% have moderate or severe care coordination needs

Participant Characteristics at Baseline

		Control n=105	Intervention n=104	p
Age in years		18.8 (1.5)	18.7 (2.5)	NS
Care coordination Tier	Low	N=53 (50)	N=53 (50)	NS
	Mid	N=28 (27)	N=28 (27)	
	High	N=24 (23)	N=24 (23)	
Discussed Transition with Provider (yes/no/don't know)		Yes (n=33, 31%)	Yes (n=38, 36%)	NS
Transition Readiness (1-10 scale) median +/-95% CI		6 (5,7)	6 (5,7)	NS

Outcomes assessed

All participants were interviewed at 0, 6 and 12 months completing:

- Patient Assessment of Care for Chronic Conditions (PACIC) which assesses six domains (20 items)
  - Patient activation (Asked how my chronic condition affects my life)
  - Delivery system design (Helped to make a treatment plan that I could carry out in my daily life)
  - Decision support (Shown how what I did to take care of myself influenced my condition)
  - Goal setting (Asked to talk about my goals in caring for my condition)
  - Problem solving (Asked for my ideas when we made a treatment plan)
  - Follow-up/coordination (Contacted after a visit to see how things were going)
- Client Perceptions of Coordination Questionnaire (CPCQ) assessing perception of patient-centered care and care coordination (32 items)
- Self-rating on a scale of 1-10 how ready they feel to transfer to adult care.
- We compared responses in intervention and control participants using contingency table analyses and relied on chi square tests to identify differences that were unlikely to have occurred by chance.

Results – 0, 6 Months

- At baseline there were no statistical differences in PACIC, CPCQ or readiness scores when comparing the intervention to control group.

- At 6 months, no differences were observed in the PACIC scores, while intervention participants rated:
  - quality of chronic illness care higher (p=0.065) and
  - reported less conflicting advice from providers (p=0.018) than the control group.

Results 12 months

- Significant differences seen in the PACIC:
    - patient activation (p=0.015),
    - goal setting (p=0.034),
    - problem solving (p=0.009) and
    - coordination/follow-up (p=0.016)

  all rated statistically significantly higher in the intervention than control group.
- Intervention participants reported:
    - More often receiving the services they thought they needed (p=0.03),
    - Were less confused about the role of providers (p=0.012) and
    - Reported more frequent discussions with providers about future care (p=0.05) than control participants.

There were no differences in self-rating of transition readiness between the two groups throughout the study period.

Discussion

- Others have shown improvement in quality by implementing systematic care coordination.
    - Lack of generalizability- limited by no control group and disease specific (disease knowledge, markers of disease, satisfaction).
- First randomized control trial of a HCT intervention examining longitudinal outcomes.
- Here we look at a population of patients with various special health care needs in the primary care setting.
- Only proof of effectiveness study (1/3rd of Triple Aim: Experience) assessing expert consensus best practices included in the 2011 AAP/AAFP/ACP Clinical Report

Results

- This HCT care coordination intervention improved many aspects of quality of chronic illness care for participants.
- Given limited resources, targeting HCT care coordination interventions for older aged adolescents/young adults and individuals with high care coordination needs may have the most impact on health services-related outcomes.

Why participate in research?

- In this case: looks as aspects of care that improve quality.
- Potential to make a difference for whole populations of individuals with the same problem/concern.
- Don’t have to have a problem to participate, sometimes comparing individuals with healthy patients without a problem can help better understand what makes a difference.
- By participating, you may get additional care and attention

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Thank you.
Any Questions? Comments?
Thoughts?

The HSC Health Care System
Caring. Serving. Empowering.

Transition of Special Needs Young Adults:

From an Insurance Company Perspective

Jalan Washington Burton, MD, MPH
Interim Chief Medical Officer

Objectives

- To provide information about the HSCSN member population
- To review our historical transition process
- To review our newly proposed transition process

ABOUT US

The HSC Health Care System

- The System is a nonprofit health care organization, serving families with complex health care needs in the Washington, D.C. area for over 130 years.
- The System combines a care coordination plan, pediatric specialty hospital, home health agency and parent foundation to offer a comprehensive approach to caring, serving and empowering people with disabilities.

A Care Coordination Plan

- Health Services for Children with Special Needs, Inc. (HSCSN) serves children and young adults up to age 26, who live in the District and receive Supplemental Security Income.
- HSCSN's care management network provides a comprehensive set of benefits, including health, long-term care and social support services for members.

HSCSN Today

- HSCSN currently serves over 5500 children and young adults with disabilities.
- Our members are mostly school-aged and live in Wards 7 and 8.
- 64% have a behavioral health diagnosis.
- Attention-deficit Hyperactivity Disorder is the leading primary qualifying diagnosis.

HISTORICAL TRANSITION PROCESS

Transition Team

- Transferred between 24 and 26 years old
- Barriers:
  - Loss of continuity
  - Lack of member buy in
  - Staffing

PROPOSED NEW PROCESS

New Approach

- One member, one Care Manager
- 16-18 years old: readiness education
- 18 years old: transition to adult providers
- 20 years old: legal guardianship
- 21-26 years old: empower members to take the lead care

Questions?

Health Services for Children with Special Needs, Inc.
Health Plan

Washington, DC's health plan for children with special health care needs

Dr. Jalan Washington Burton

jburton@hschealth.org

CHILDREN'S NATIONAL HEALTH SYSTEM

PARENT NAVIGATOR PROGRAM

TRANSITION INITIATIVE

CTSI-CN Science Café 360

April 26th, 2017

TjaMeika Purnell Davenport, Parent Navigator

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Parent Navigator Program

- **Mission**: To provide non-medical assistance and support to families of children with chronic medical conditions and special health care needs
- Seek to inform, educate, support, and advocate for families of children with special health care needs
- Empower families to be strong partners with their providers while providing guidance for families to advocate for themselves.

How Navigators Help

- Offer peer to peer support
- Provide a listening ear
- Coach families on how to become more effective advocates for their children
- Help families prepare for appointments
- Assist in communication with doctors, nurses, and healthcare professionals
- Link families to services and other supports such as:
  - Community Resources
  - Educational Services
  - Health Insurance
  - Respite Care
  - Transportation
- Build partnerships with organizations and community agencies

How Navigators Help Con't

- **Navigator:**
  - Can assist families with establishing goals for healthcare transition beginning at age 14
  - Can refer families to legal assistance resources for Guardianship/Supported Decision Making options by age 18
  - Can assist families with preparing for educational transition by age 16
  - Can assist with providing resources for specialty appointments outside of the Children's network
  - Can encourage patients to assume increasing healthcare responsibility
  - Can assist providers in understanding family dynamics

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Thank You!

☐ Questions

☐ Discussion

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