Transition from Pediatric to Adult-based Care for Youth with Special Health Care Needs

Youth Transition to Adult Health Care: An Outcomes Approach Summit
December 12, 2012
Title V CYSHCN, UW Health – American Family Children’s Hospital and Children’s Hospital of Wisconsin
Goal

The audience will understand the role of outcomes-focused quality improvement in optimizing health care transition of youth with special health care needs from pediatric to adult-based care.
Objectives

The audience will be able to discuss:

1) The definition of special health care needs (SHCN)
2) Epidemiology of SHCN
3) Why health care transition (HCT) is important
Objectives (cont’d) –
Audience will be able to discuss:

4) Barriers / factors that affect HCT
5) Key elements in developing a HCT program
6) What we have done in developing the TCH Transition Program
Objectives (cont’d) – Audience will be able to discuss:

7) TCH Transition Program QI Project
   Outcomes (System, Process, Clinical)

8) Examples of small tests of change

9) Program evaluation
Objective #1: Definition of SHCN

Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

(MCHB. Newacheck, 1998)
Objective #2 – Epidemiology
CYSHCN in Wisconsin

- Wisconsin - 16% or 201,000 individuals.
Objective #3

Why is HCT important?

- 90% of children with chronic illness and disabilities survive into adulthood
What is the outcome after transition for CYSHCN?

“Many YSHCN appear to make the transition to adult health providers successfully, some experience serious gaps in outcomes; those with more complex conditions or with conditions affecting the nervous system appear to have less good transitions.”

Bloom JAH 2012
Objective #4
Barriers to/factors affecting health care transition and proposed solutions
Hoan Bridge, Milwaukee
Barriers

- CYSHCN - not prepared for HCT;
- Pediatric practices - not prepared to assist in transition readiness for CYSHCN & families;
- Inadequate communication between subspecialty and medical home
- The adult health care system - not prepared to receive YASHCN into the adult health care system.
Objective #5 - If you are going to develop a transition program, what else should be considered, in addition to those barriers just mentioned? (Position Statement. SAHM, 2000)
4 components to the transition plan

AAP/AAFP/ACP 2011

- Assess transition readiness
- Write a realistic transition plan
- Implement the plan through education
- Monitor progress
- (Author) – enhance communication with adult side
Family/professional support – necessary but not always there

Adult health care systems
- Less holistic; Less coordinated
  – “fragmented”  Valenzuela 2011
- Less collaborative
- Expect more independence
- Prepare patients and families for this cultural change
Transfer decision-making to teen

- Family’s resistance (?) Steincamp 2001
- Some families impede transition - Disabled youth vs. healthy sibs:
  - less likely to initiate conversations
  - more likely to be ignored
  - negative reactions from parents when they initiated a conversation. Saetermoe 1999
Transfer decision making to the teen (cont’d)

Care coordinator, partnered with youth and family
Providing care *with* rather than to youth
Written transition plan by 14
Training in transition

Identify, teach core knowledge and skills to provide transition care
Consensus, Pediatrics 2002

Invite parent out of room, as appropriate – models for parents
Confidentiality, as appropriate

HEADDS - + Youth Development

Sexual health: GU exams, birth control
Recognize, refer mental health conditions
Health education – written plan

What is the name of your diagnosis and how is it treated?
Do you take your meds/treatments?
What requires urgent medical attention?
What to do during an emergency?
Objective #6: What are we doing at TCH to address these key elements?

First a chronology
Chronology of Transition Program at TCH

- 1999 – D.C.
  - First 5 annual Transition Conferences
- 2004 TCH Transition Committee formed
- No written transition policy
Survey of TCH Clinic Chiefs 2004

- Age new patients not accepted: 16-26
- Routinely transition to adult MD: 9/13
- Protocol for transition: 1/13
- Adult MDs to refer to: 6/13
- Service wants help with transition: 10/12
First Transition Committee Meeting

- Many services represented
- They wanted a simple answer to a complex question - 2004
  - What can you do to help me transition my patients? Often with urgency
  - We said we’ll build the TPT, you’ll use it
Raising awareness – 2004 - 08

- Hospital publications
- Ambulatory Nursing Council
- Social Work Department
- Parent groups: IBD
- TCH Family Advisory Board
- First BCM Transition Clinic formed in Med-Peds Program
Objective #7: Looking at Outcomes

- Structure
- Process
- Clinical

Donabedian 1966
Developed the TCH Transition Planning Tool (TPT) 2004 - 08

- Reviewed literature
- Reviewed existing tools
- Developed TPT
- Parent and teen input > revisions
- Will review the TPT later
Some Lessons Learned
2004 - 08

- Practicing transition planning is a quantum shift in medicine (2004 – present)
- It takes years to develop a program
- We needed more infrastructure support from 2004 - 08
  - TCH Transition Committee – volunteer
Implementing the TPT: 2008 - present

- Structure
- Built the TPT into Logician (2008)
  - $15,000 grant to write program
- Pilot study: Obtained feedback from clinicians, patients, and family members
- Revised the TPT, implemented 2nd pilot study in 5 clinics
- 1st IRB protocol – 13 clinics
Process of implementing the TPT (cont’d)

- Texas Title V Division of Service for CSHCN contract
- TCH and contract > 2 FTE (2009)
- Implemented TPT **(Process)**
  - Inserviced staff
  - Monitored TPT use
Process of implementing the TPT (cont’d)

- 2011
  - First PAS presentation of TPT data
  - TCH switched EMR to EPIC
  - “No customization”
  - Rebuilt the TPT into EPIC (Structure)
Now back to Objective #6: What are we doing at TCH to address HCT

- TCH Transition Program - Adult
  - Addressing the lack of adult providers
  - Supporting the BCM Transition Clinic
- Preparing for transition at TCH
TPT

- Start at age 11
- Ask ≥ of 13 core questions each visit
- Any clinician can ask the questions
- A test of mastery
  - Assess knowledge and skills in key areas
  - If adequate > “Goal met”
    - No need to reassess
  - If patient/parent has not mastered the knowledge/skill
    - Activities to help them master the knowledge or skill
Transition Planning Tool (TPT)
- Promotes independence
- Health education knowledge and skills
- Professional training
- Assesses readiness
- Provides a medical summary
TPT: Age 11-13

- Can you tell me about your disease/disability?
  - Patient is able to explain their illness: “Goal Met” – recorded in note
  - If not able to explain disease:
    - Team member to provide **written information** on (Clinic Specific)
    - Consult appropriate team member for diagnosis explanation
    - Print an **activity page** for patient to complete (Learning and Expressing your Heath Condition)
Written information and activities to help patients become transition ready*

Written information or activities:
- Ex) Fact sheets on the illness or meds
- Ex) Handouts about making an appointment
- 80 handouts, 70 in Spanish

*will define later
TPT: Age 14 – 16

Did you meet with your doctor without your parents and ask questions today?

- Patient to ask questions of staff independently. If they do: “Goal Met.”

Please select a plan of action:

- Print activity page for patient to complete (My Heath Care Questions)
- Team member to encourage patient to ask questions of medical providers
- Address questions directly to patient and encourage patient to respond
TPT – Reproductive health

- When was your last menstrual cycle? How do you track your cycles?
  - Patient verbalizes date of last menstrual period and expected date of next cycle: “Goal Met.”
- Or, select a plan of action
  - Team member to review tracking of menstrual cycle with patient
  - Print calendar for tracking of cycle (Menstrual Cycle Record)
TPT: 17 and older

- How do you fill and refill your prescriptions?
  - If they know this: “Goal met”
  - Given home work if not able to do so.
What to include in the summary note to the adult MD

- Problem list
- Recent surgery
- Recent imaging
- Meds
- Immunizations
- Recent labs/other tests

- MD, others providing care, phone # and contact info
- Contact info of pharmacy, equipment
- Data stick, hard copy
AIM-FAST

_An Innovative Model for Facilitating Adult Services Through Transition For Children and Youth with Special Health Care Needs Addresses Objectives #7-9_
Grant support

- Department of Health and Human Services, Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs
- Grant D70MC23045.
Purpose (Clinical outcome)

- Increase the percentage of Texas Children’s Hospital (TCH) patients with complex congenital heart disease, HIV/AIDS or sickle cell disease, who successfully transition to adult-based care by improving health care transition readiness.

- Understand the causes of health care transition failure in these three patient populations.
Definitions

**Transition Eligible**: Based on age and/or insurance.*
Ex) 19 years old and on Medicaid

**Transition Readiness**: Patient has achieved a level of health care transition knowledge.*
Ex) Correctly answering 50% of the 13 core TPT questions

*As defined by medical service.
Definitions (cont’d)

- **Transition**: Patient transferred to adult-based care.
- **Successful Transition**
  - Having 2 visits in the 1st year
  - Providing the PMS at 1st visit
  - Maintaining clinical status
  - Correctly answering 50% of the 13 core TPT questions
Program Evaluation: Process outcomes

- Number of providers using the TPT
- Number of patients with whom the TPT is used
- Number of 13 core questions asked
- Number of core questions answered correctly: “Goal met”
Credentialing users of TPT
(Process)

- Identified interested MDs, nurses, social workers on each service
- In service to the group
Challenges and Strategies in Training Staff to Use the TPT

- Many MD’s are not interested in using the template
- EPIC weekly reports
- PDSA cycles
  - Monthly meetings
  - Use of other providers
  - One on one demonstration
More PDSA Interventions

- Scanning clinics the week before to see which patients are eligible to use the TPT
- Sending those names to clinics
- Meeting the providers in clinic
- Quarterly all-user’s meetings
Process outcomes (cont’d)

- Patient interviews
- Family interviews
- Provider interviews
  - Led to reducing the number of questions to 13 core questions, of a total of 27
Clinical outcomes

- Meeting with all adult clinics who will see the TCH transitioned patients
- Meeting with patients in the adult clinics
- Assessing for transition success
Program Evaluation - Outcomes

- **Structure**
  - Is the TPT in place

- **Process**
  - Weekly EPIC reports on # of users, patients exposed to TPT

- **Clinical**
  - Ultimate outcome

*Donabedian 1966*
Summary of HCT

1/5 households in U.S. have CYSHCN

Transition

- Desirable, intuitive, necessary
- Youth are surviving longer yet they, their families & systems are not prepared for HCT
- A process, not an event

Barriers – lack of adult capacity
Summary (cont’d)

Key elements to HCT - Pediatrics

- Professional and family support
  - Professional training
- Transfer decision making gradually
- Care coordination – evidence that it works; can save $
Summary (cont’d)

- In developing a program, 3 types of outcomes to be considered
  - Structure
  - Process
  - Clinical
- This will take years
- Need to have evaluation component for each outcome
- Need to increase adult capacity
14th Annual Chronic Illness: Transition from Pediatric to Adult-based Care

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Thank you