Transition from Pediatric-based to Adult-based Care

The Leadership Education in Adolescent Health Training Programs

2010

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Goals: The audience will understand:

1. The current status of transition planning for CYSHCN in the U.S.
2. Recent collaborative LEAH activity
3. Lessons learned in creating a transition program at one LEAH program

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Objectives: The audience will be able to discuss:

1. The current status of transition planning for CYSHCN in the U.S.
2. A LEAH CE/DL collaborative project to improve the MCH infrastructure for transition planning
3. Lessons learned in developing a transition program at one LEAH site

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How are we doing with transition planning?

1984

- U.S. Surgeon General – need for transition services

2002

- Joint statement (AAP, AAFP,ACP/ASIM) Consensus Statement need for improved transition services

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Core transition process outcome

- 4 components: Discussions with health care provider about
  1. Future adult health care needs
  2. Finding an adult provider
  3. Securing health insurance; and,
  4. Taking more responsibility for their care

2005-06 NS-CSHCN Lotstein 2009

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Core transition process outcome

- 41% of parents of CYSHCN reported that this core process was occurring.
- 62% - their doctor or other HCP talked with them about adult health care needs.
- 34% reported discussions re: upcoming changes in health insurance.
- Lower for low SES, no medical home

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Effective strategies to engage the adult health care system are lacking

- Families and youth are having difficulty finding adult providers to treat their special health care needs

Rosen 2003, Scal 2002

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Communication between pediatric and adult providers is inadequate

- Fewer than 50% of adult providers communicated with the previous provider, yet 90% wanted to

There is room for improvement

- Training health care providers
- Training in systems of care
- Communication between pediatric and adult providers/systems
- Suggestions for improvement?

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Critical 1st steps for successful transition to adult-based care Consensus statement

(AAP, AAFP, ACP-ASIM) Pediatrics 12/02

1. Care coordinator, partnered with youth and family

- http://www.hrtw.org/

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Consensus statement (cont'd)

2. Identify and teach core knowledge and skills to provide transition care
   - Invite parent out of room, as appropriate
   - Confidentiality, as appropriate
   - HEADDS
     - Sexual health: testicular, pelvic exams
     - Birth control
     - Recognize and refer mental health conditions
   - Residents, CME

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Consensus statement (cont'd)

3. Up-to-date medical record
4. Written transition plan by 14

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LEAH Needs Assessment - 2010

- N=137, 19 states, through state MCH programs
- Results:
  - Educational content
    - Reproductive, behavioral, oral
    - Systems: professional training in transition planning, preparing medical records, timing
  - Internet based distance learning is preferred – access at any time

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CE/DL Collaborative LEAH Program Proposal

- Internet based
  - LEAH, HRTW, ICHP, NYYAAC
  - National Youth and Young Adult Advisory Brd
  - Work closely with State Title V program
  - Work with other MCH partners
  - Expand to the broader MCH community, professional organizations
- Content driven by the needs assessment

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LEAH Program Capacity to network with other MCH partners

- LEAH Projects in 6 Regions: I Harvard, II Rochester, III Johns Hopkins, V Indiana and Minnesota, VI Baylor and IX UCSF
- Capacity to network:
  - Collaborative relationships with Title V, MCHB training programs, i.e. LEND in their cities, regions
  - Ex) National Initiative to Improve Adolescent, National Adolescent Health Information Center, Konopka Institute

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Baylor LEAH program's experience with transition activities, locally (TCH)

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Mission Statement of the TCH Transition Committee - 2004

To further the transitioning process from pediatric to adult centered care for families, adolescents and young adults with special healthcare needs.

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Building the Transition Template

Interdisciplinary representation: medicine, nursing, social work, child life, HIS

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Survey of Clinic Chiefs

- 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

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Building the template (cont'd)

- Reviewed existing research, programs and tools
- Presentations to Family and Teen Advisory Boards – editing of template

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Building the Transition Template (cont'd)

- Built resource lists
  - Accepting MDs
  - Fact Sheets: insurance, family planning, community programs
- Built interactive worksheets for patients
  - Explaining your illness, taking your meds

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Volunteer/In-kind support

- TCH Administrative interns
- Community resource list
- Adult care provider list
- Development of new fact sheets and information packets
- Template development: Grant, TCH

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Building the Transition Template (cont'd)

- Hospital information system
  - $10,000 grant from TCH Development Office to develop the template, 2006
- TCH Transition Team

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The Electronic Transition Template

- An assessment tool to facilitate the transitioning process
  - Starts transition checklist at age 11
  - Divided into age groups: 11-13, 14-16 yo
  - Each question is addressed with patient
  - Appropriate follow up if patient cannot accomplish intended skill

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EMR Template

Transition Assessment Form

☐ Pt is developmentally unable to answer questions please address caregiver

Age 11-14	Age 14-16	Age 17-19	Final Transition	Caregiver

Skill	Unable to Perform	Partially Performs	Skill Accomplished
Pt. is able to explain basic knowledge of diagnosis? Pt. should be able to verbalize basic disease process	☐	☐	☐
Pt. is able to verbalize list of medications, doses and what each is for? Pt. is able to state medications and dosage	☐	☐	☐
Pt. knows health emergency phone numbers and physician name and number? Patient should be able to verbalize the 911 emergency number and appropriate contact information for all of his/her physicians	☐	☐	☐

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Transition Assessment Form

☐ Pt is developmentally unable to answer questions please address caregiver

Age 11-14	Age 14-16	Age 17-19	Final Transition	Caregiver

Skill	Unable to Perform	Partially Performs	Skill Accomplished
Pt. is able to explain basic knowledge of diagnosis? Pt. should be able to verbalize basic disease process	☒	☐	☐

Please select a plan of action:

- ☒ Print out a diagnosis specific fact sheet
- ☐ Consult appropriate team member for diagnosis explanation
- ☐ Print out an activity page for patient to complete

Pt. is able to verbalize list of medications, doses and what each is for? Pt. is able to state medications and dosage	☒	☐	☐

Please select a plan of action:

- ☐ Medical staff reviews medications with patient
- ☐ Print medication activity sheet for patient to complete
- ☐ Print a medication fact sheet

Pt. knows health emergency phone numbers and physician name and number? Patient should be able to verbalize the 911 emergency number and appropriate contact information for all of his/her physicians	☐	☒	☐

Please select a plan of action:

- ☐ Print out activity page for patient to complete with physician and 911 numbers
- ☐ RN to address importance of carrying physician contact numbers
- ☐ Provide card with physician name and numbers
- ☐ Reminder for next visit: Request that patient verbalize appropriate emergency call numbers to include 911 and physician contact information.

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Pilot project for use of transition template

- In-service to interested clinics
- Live in 4 clinics, April 2008
- Focus groups after 6 months
  - Technical support for staff – not there
  - Physicians – trying, “not enough time”
  - Transition template - Needs to be made more user friendly and it’s use promoted

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Pilot project (cont'd) - 2009

- 57 patients/families consented
- 52 have evidence of transition planning manifest in use of the transition template in the EMR
- Users
  - Social work - 28
  - Nursing – 21
  - Medicine - 5

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Current study

- Funded by Texas Department of State Health Care Services/Title V Division of Children with Special Health Care Needs
  - Quantum leap
- September 2009 - 2 full time staff
- Purpose: To conduct a preliminary evaluation of the transition template as it is being used in TCH specialty clinics

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Process outcomes in current study

- Evidence of a transition plan in the EMR
- Patient satisfaction
- Family satisfaction
- Provider satisfaction

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Current study (cont'd)

- Retrovirology, Dialysis, Neurology, Special Needs Clinic, Endocrine, GI, A/I, Sickle Cell
- Eligible patients: ≥12 years of age seen in TCH outpatient clinics for specialty care > 2 times/year

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Current study (cont'd)

- In-service on use of template for providers
  - Social work, nursing, medicine
- Credentialing
  - Use of template

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Current study (cont'd)

- User's group
- Each service needs a champion
- Results expected in 2011
- Plan is to go system wide

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Summary

- 41% of parents report that core transition process outcome is occurring for CYSHCN
- Many contributing factors: poor communication between pediatric and adult providers, inadequate training, lack of concise medical record at transition
- The LEAH Program has significant networking capacity to market, disseminate and diffuse a curriculum

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Summary (cont'd)

- Building a transition program is a long process
- Identified personnel must be hired to bring the project to scale
- There must be a champion for each service
- Acceptance by some services is immediate, others slower

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Thank you