HEALTH CARE TRANSITIONS: INTEGRATING HEALTHCARE AND EDUCATIONAL GOALS

Rebecca Boudos, LCSW
Spina Bifida Clinic
Transition Specialist
Lurie Children’s

Parag Shah, MD
Chronic Illness
Medical Director
Lurie Children’s

Melinda Remaly, Ph.D
Director of Transition Services
Niles Township High School District 219

What do we mean by “Transition” in schools and health care

Identify health care skills and goals for a successful health care transition

Discuss incorporating health care transition goals into the school setting

Discuss ways to enhance communication between the teen, family, school, and medical providers

Tips and Resources

OBJECTIVES

- What do we mean by “Transition” in school and health care
- Identify health care skills and goals for a successful health care transition
- Discuss incorporating health care transition goals into the school setting
- Discuss ways to enhance communication between the teen, family, school, and medical providers
- Tips and Resources

TRANSITION

EDUCATION TRANSITION
- Adolescent → Adulthood
- Increased Independence
- Developing adult life skills
- Integration into community
- School → College/Vocation
- Post-high school planning

HEALTH CARE TRANSITION
- Transfer of care
- Adult health care providers
- Medical competency
- Increased responsibility for medical care
- Medical competency
WHAT IS TRANSITION?
AN EDUCATIONAL PERSPECTIVE.

The collaborative and coordinated “process” of planning and service delivery that enables students who have disabilities to successfully attain their post-secondary goals.

BEST PRACTICES IN TRANSITION

- Engages students, parents, educational team, medical team and service providers through collaboration and ongoing reciprocal communication.
- Is student centered.
- Is based on SPIN...student’s needs, strengths, interests, and preferences.
- Promotes students’ self determination through active student involvement throughout the process.

Transition Planning in Schools....

- Begins at age 14-1/2 in Illinois
  (Federal law requires transition planning to begin at age 16)

Transition Planning Must Address....

- Post-secondary education and/or training
- Vocational education and employment
- Adult Services (Guardianship, Estate Planning, Insurance, SSI, Medicaid...)
- Recreation and leisure
- Independent living and community participation
WHAT DOES HEALTH HAVE TO WITH IT?

- Students must be healthy to succeed in school, work, and the community.
- Students that are more active in chores/work/educational environments take better care of their health.
- Students with chronic conditions must learn to manage their medical condition and take on more responsibility and decision making in their health care.
- Transition planning must occur in collaboration with the medical team, at home, school, and community.

OVERALL GOAL OF TRANSITION

- To ensure successful transition from childhood to:
  - Maximal independence and social connectedness.
  - Education and/or vocation integration.
  - Increased medical competency and responsibility.
  - Preparation for adult health care.

WHAT IS HEALTH CARE TRANSITION?

“the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”

(AAP Clinical Report 2011)
PEDiatric VS. ADULT MODELS
OF HEALTH CARE: WHY PLANNING IS IMPORTANT

Pediatric
• Provider & parent controlled
• Comprehensive, multi-disciplinary clinics
  (one-stop-shopping)
• Case management & social work support
• Families supported through process

Adult
• Patient responsible
• Multiple providers each caring for separate issues
• Less social work or case management assistance
• Patient must be proactive to get services

SIX CORE ELEMENTS: BEST PRACTICE GUIDELINES FOR HEALTH CARE TRANSITION

1. Develop a transition policy
2. Identify youth that are going to be difficult to transition
3. Assess youth for transition readiness
   (CHECKLIST)
4. Develop tools for transition
   a. Portable medical summary
   b. Emergency plan
5. Transfer care
   a. Summary
   b. Communication with new provider
   c. Condition fact sheet if necessary
6. Completion of Transition
   Continue to be a resource

ASSESSING AND PREPARING YOUTH

Knowledge
Skills
Responsibilities

USE A CHECKLIST TO HELP
**CHECKLIST EXAMPLE**

- Know name of condition
- Know symptoms of condition
- Know names of medication and purpose
- Know names of doctors and purpose
- Know how risk taking behaviors may affect medical condition
- Know where to go in an emergency
- Know basic information on insurance plan

**KNOWLEDGE**

- Have teen describe their illness in 3 sentences
- Have them learn about their medical history from their parent, major hospitalizations, surgeries, medicines etc.
- Have teen and family create a portable medical record

**EXAMPLES KNOWLEDGE: MEDICAL SETTING**

- Have teen describe their illness in 3 sentences
- Have them learn about their medical history from their parent, major hospitalizations, surgeries, medicines etc.
- Have teen and family create a portable medical record
SKILLS
- Speak directly to your medical team
- Meet alone with your medical team
- Call the nurse yourself
- Make an appointment
- Manage self care and medical skills
- Fill a prescription or medical supplies
- Take medications

EXAMPLES SKILLS AND BEHAVIOR: MEDICAL SETTING
- Speak directly to teen so they can learn to communicate
- Direct teen to front desk to make the appointment themselves
- Have teen prepare some questions to ask the doctor about their condition
- Ask directly about barriers to medical adherence
- Use resources (technology, pill boxes) to help improve compliance
  - www.Mymedschedule.com

WHAT SCHOOLS CAN DO
- IDEA (Individuals with Disabilities Education Act)
  - IEP or the Individual Education Plan
- ADAAA (Americans with Disabilities Act Amendment Act)
  - 504 Plan
- Individualized Health Care Plans
- Emergency Care Plans
CASE EXAMPLE 1: MEDICATION AND STRESS

- Susy, 16yo female, with Insulin Dependent Diabetes and anxiety in both regular and honor's curriculum.
- She cannot describe her condition well.
- She currently does not know how to check own blood sugar and does not know formula for calculating insulin dosing.
- Health Care Goal: Manage and self administer insulin and manage stress
- Has 504 plan. Plans to attend college out of state.
- Both disease and anxiety interplay to affect school work, med management and future planning.
- How to manage so does not miss more school?

CASE EXAMPLE #1: MEDICATION AND STRESS

- Transition Goal:
  She will learn to check her own blood sugar and review how to calculate insulin dosing
  Susy will use an alarm to remind herself to check her glucose at lunchtime.

- Who is involved?
  Social worker/school counselor can assist with stress management and academic planning. Nursing involved with insulin teaching and administration.

- Counseling, medication management, teen websites

My Med Schedule

www.mymedschedule.com
CASE EXAMPLE # 2: MAKING APPOINTMENTS

- James, 20 yo, with spina bifida. Currently is reminded by school nurse regarding self-catheterization. Will be transferring care to adult spina bifida clinic. His mom always used to make appointments, but he is practicing his communication skills and taking more responsibility for his health care.

  - Health care goals:
    - Make adult health care appointment
    - This health care skill can be applied to other skills: ordering a pizza, calling the pharmacy, calling a friend
    - Perform catheterization without reminders

CASE EXAMPLE # 2: MAKING APPOINTMENT

- Transition goals:
  James will call to make an appointment at adult spina bifida clinic before his 21st birthday. James will remind nurse and self cath 3x/day
  James will complete a health summary using MY HEALTH PASSPORT before his first adult appointment.

- Who is involved?
  May be occupational therapist and nurse in commutation with his medical social worker.

- Videos, role playing, health passport
SUMMARY OF GOALS OF TRANSITION

- Teens with chronic illness are surviving childhood, but their path to success needs to be streamlined.
- Transition involves planning for teens’ future in school and work, community, relationships and medical care.
- Transition planning helps students make informed choices and take charge of the process.
- Adolescents will achieve the most when they learn and master the skills needed for success.
- Transition is a process, not an event.
- Start early!
“One of the key ways we define ourselves and develop a sense of identity is through choices we make while navigating the transitions in our lives. Fostering a sense of self-determination during the transition process is critical to promoting successful transitions for students both with and without disabilities.”

RESOURCES

- DSCC Transition: http://internet.dscd.uic.edu/dsccroot/parents/transition.asp
- Health Care Transitions: HTTP://HCTRANSITIONS.ICHIP.EDU/HCT_PROMO
- KU Transition Coalition: www.transitioncoalition.org
- NSTTAC: www.nsttac.org
- NASDSE: Communities of Practice: www.sharedwork.org

RESOURCES

- National Center on Secondary Education and Transition: www.ncset.org
- NICHCY: www.nichcy.org
- DCDT Transition Standards: http://www.dcdt.org/
  California: www.calstat.org/transitionGuide.html
- Illinois State Board of Education: www.isbe.net

CONTACT INFORMATION

- Rebecca Boudos, LCSW rboudos@luriechildrens.org
- Parag Shah, MD Pshah@luriechildrens.org
- Melinda Remaly, Ph.D melrem@219.org