Comprehensive, Coordinated, Collaborative Care

American Academy of Pediatrics
Family Voices
Maternal and Child Health Bureau
National Association of Children’s Hospitals and Related Institutions
and
Shriners Hospitals for Children
Learning Objectives

• Understand care coordination’s role within the medical home concept.
• Acknowledge strategies for chronic care management within the primary care office setting.
• Recognize the role and importance of the community within a medical home.
• Understand different community-based service systems.
• Identify collaboration strategies with families, children and youth with special health care needs (CYSHCN) and community-based services.
• Apply the learning objectives to the given case study.
Section One: Why Provide Comprehensive, Coordinated, Collaborative Care?
What is comprehensive care?

- Continuous care
  - 24 hours a day
  - 7 days a week
  - 365 days a year

- Requires competence by the physician & medical staff to care for CYSHCN

- Involves medical; developmental; educational; recreational; vocational; psychological and financial issues
Why is Comprehensive Care Important?

CYSHCN and their families/caregivers typically have multiple needs:

- Medical and health
- Developmental and educational
- Psychosocial
- Financial
- Family support service
How is care coordination a part of comprehensive care?

Physicians can’t “do it all”
- Not much training
- Not much time

Families may have unmet needs
- Information, coordination of services
- Unvoiced needs
- Needs may be more than physician perceives
Why is Care Coordination Important?

Families spend 11+ hrs/wk coordinating care for CYSHCN, which has consequences for:

- Emotional/mental/ behavioral health of family and CYSHCN
- Finances
- Employment

MCHB/NCHS. National Survey of Children with Special Health Care Needs. 2002
Care Coordination:

- Is a collaborative process
- Involves families, educational, social service and medical providers
- Ensures access to appropriate community-based services
- Advocates for the comprehensive community-based service systems

Donati, B; Passerello, T; Stille C. Coordination of Care in the Medical Home. Presented at: National Association of Pediatric Home and Community Health Conference; October 3, 2003; Mystic, CT.
Goals of Care Coordination

To promote the well-being of families and CYSCHN through:

- Information and referral
- Consultation
- Training
- Outreach
- Collaboration
- Service coordination
- Optimization of insurance and public benefits
Care Coordination: The Medical Home Physician’s Role

- Gathering information, triage: medical; non-medical; “in-between”
- Interpret medical information; integrate it all into care plan
- Teach CYSHCN and families
- Learn from CYSHCN and families
- Mediate any potential conflicts

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Care Coordination: What does it look like?

- A plan of care developed by the physician, CYSHCN, and family
- A central record with pertinent medical information kept in the primary care office
- When CYSHCN is referred for a consultation, the medical home assists the CYSHCN and family in communicating clinical issues
- The medical home evaluates and interprets the consultant’s recommendations for the CYSHCN and the family
- The written care plan is coordinated with other community agencies
Section Two: How Do You Coordinate Care From a Primary Care Perspective?
Chronic Care Management (CCM):

6 actions

- Proactive decision to provide CCM to identified CYSHCN
- Provision of care intertwines CCM with other areas of primary care services
- Continuous communication with family
- Establishes necessary procedures in the primary care office
- Initiates continuous CCM
- Develops and maintains collaborative relationships among the CYSHCN’s community agencies and providers
Chronic Care Management: Making the decision

A primary care office staff should acknowledge the need for CCM strategies when a child/youth’s health condition meets the following criteria:

- significantly impacts daily living and family life
- impacts school performance
- impacts development
- involves on-going specialty care
- involves several providers and agencies
- causes new predicament/ emergency
Chronic Care Management:

Creating a plan

• Developed in concert with the PCP; family; CYSHCN (if developmentally appropriate); care coordinator (if appropriate)
• Addresses: goals; concerns; interventions; services; referral contacts for medical and non-medical needs
• Includes: medical information; visit schedules; communication strategies; other agencies services
• Continuously updated and assessed
• Family/CYSHCN are provided with copies of care plan
Chronic Care Management:
The provider’s role with the family/CYSHCN

- Communicate office procedures to the family/CYSHCN
- Discuss & assess what family/CYSHCN support resources are available/needed
- Identify roles and expectations for all
- Discuss time lines and possible agendas for provision of care
Chronic Care Management: The Family’s/ CYSHCN’s Role

- Act as a partner
- Communicate directly and honestly with providers
- Responsibly manage care notebooks to assist in communicating needs to provider(s)
- Bring notebook to provider appointments
- Continuously assess care plan and its integration into life-activities
Chronic Care Management:

Putting the office systems in place

- Establish system to “flag” or “identify” CYSHCN’s medical chart
- Establish system to alert office staff to schedule longer visit times for identified CYSHCN
- Identify primary office contact person for family
Chronic Care Management: Putting the plan to work

- Assess the care plan
- Monitor involvement of specialists
- If a service gap or conflict is identified, review & revise plan
- Use direct communication strategies between physician and family/CYSHCN
Chronic care management: Co-Management between PCP and Specialists

- Institute of Medicine (IOM) and AAP have identified PCP-specialist communication as important element in the medical home
- Specialists communicate assessment results to 51% of PCPs
- Specialists outline co-management of CYSHCN care plan in only 31% of cases
Co-Management between PCP and Specialists: Barriers

- Timeliness of communication
- Telephone difficulties
- Specialists referring to other specialists without PCP involvement
- Families seen as central method of communicating between providers

Co-Management between PCP and Specialists: When communication is essential

- PCP and family make initial decision to refer
- Specialist has conducted assessment and outlines plan for diagnosis/treatment
- Follow-up care by either provider is significant to managed care plan

Co-Management between PCP and Specialists:
Possible strategies

- Send a referral letter and supporting materials from PCP prior to specialist consultation.
- Create a list of providers being seen by each CYSHCN to note who PCP should be in communication with.
- Establish common procedures for all providers to use when email is frequent medium to communicate.
- Identify strategies for specialists to educate PCP on certain chronic conditions.

Chronic Care Management:
How can the practice be supported financially?

- Use of appropriate CPT codes is essential
- Establish proper documentation of utilization and consultation
- Understand the different type of applicable codes for care coordination
Section Three: How Do You Provide Coordinated and Comprehensive Care Within the Community?
Barriers to Accessing Community-based Services

- Navigation of several systems of care with various rules, procedures, personnel and eligibility criteria
- Rarely no single point of entry
- No single agency is responsible for all services
- HIPAA is perceived as barrier
Additional Barriers

- Fragmented and categorical service systems
- Service systems and health care systems are often not linked
- Different systems use different terminology
- Service systems are often geographically dispersed, raising time and transportation challenges
Advantages of Community-based Care for Providers

- Provider is more likely to be familiar with a community’s health & social issues
- Provider is able to promote the health and well-being of all children in a community
- Provider is more likely to be accessible to a community’s service systems
Advantages of Community-based Care for Families

- Minimize disruption of family life, work & school
- Keeps family connected with community
- Supports family and community values
- Encourages healthy, stable relationships
- Builds upon family’s strengths; maximizes their decision-making power
Providing community-based care: Provider’s Role

- Establish office procedure for staying aware of community services
  - As part of care coordinator’s responsibilities
  - Collate local resource directory
  - Establish regular meetings with community providers
  - Assess needs of family and CYSHCN for community services
Accessing community-based care: Family’s/CYSHCN’s Role

- Acknowledge needed supports and resources
- Provide honest assessment of current services/resources
- Inform physician and office staff of additional community-based resources
Considerations for provision of comprehensive care: Medical Issues

- Is there a recent and comprehensive medical history available?
- Has medical information been communicated in understandable terms?
- What procedures are in place for discharge planning?
- Has “medical necessity” been defined?
- How does family feel about managing medical needs at home?
- Has care plan been reviewed by family? Medical contacts identified for family?
- What communication strategies are in place between the medical home and other providers?
Community Resources & Agencies: Medical

- Books, articles, disease-specific hand-outs
- Parent notebook of CYSHCN’s condition
- MH/MR/DD/ Title V state programs
- Respite programs
- Child care facilities
- Extended care facilities
- Home care agencies
- Durable Medical Equipment companies
Considerations for Provision of Comprehensive Care: Developmental Issues

- What early surveillance and screening procedures have been performed?
- What therapies are needed? Accessible?
- Has referral been made to Early Intervention? Has Release of Info been sent? Follow-up completed?
- What communication strategies between the medical home and other providers have been established?
Community Resources & Agencies: Developmental

- Early Intervention
- Head Start
- Community-based therapies (PT/OT/Speech)
- School system
Considerations for provision of comprehensive care: Educational/ Vocational Issues

• How will the CYSHCN access educational system?
• Has an Individual Educational Plan or 504 been developed with guidance from medical home?
• How has the Individuals with Disability Education Act been incorporated into educational plans?
Community Resources & Agencies: Educational/ Vocational

- Special education districts, boards, committees
- Vocational rehabilitation programs
- Easter Seals
- Condition-specific associations
Considerations for provision of comprehensive care: Recreational Issues

- What are CYSHCN interests regarding exercise/recreation? Goals? Dreams?
- What are possible effects of medication on exercise/recreation?
- What is current level of fitness? How does that affect selection of which exercise/recreation to participate?
- Has medical home physician been aware/involved in selection of exercise/recreation activity?
Community Resources & Agencies: Recreational

- Special programs; camps
- A community’s recreational department
- A community’s Special Education district
- Transportation
- Family resource centers
Considerations for provision of comprehensive care: Psychosocial Issues

- Has a detailed psychosocial history been taken?
- What is the impact of CYSHCN’s condition on family?
- What is the impact of family’s dynamics on CYSHCN?
- Has an Individual Family Support Plan been developed?
- What was the medical home physician’s role in that development?
- What current support groups are being used by family/CYSHCN?
- Has “Do Not Resuscitate”/comfort care issues been discussed?
- Has guardianship or other legal issues been discussed?
- Have there been discussions about possible death & bereavement?
Community resources & agencies: Psychosocial

- Mental health community clinics
- Behavioral health community clinics
- Mental health boards
- Family resource centers
- Foster care
- Hospice
Considerations for provision of comprehensive care: Financial Issues

- What are current payment options offered by your primary care practice?
- If there are changes in the family’s/CYSHCN’s insurance, are they accommodated?
- Is the billing process flexible to meet needs of different health plans?
- Is there an office system established to continuously provide financial resource information to families/CYSHCN?
- What is the medical home’s understanding of different health plans & financial resources?
Community resources & agencies:

Financial

- Medicaid and Medicare
- Title V CSCHN program
- SCHIP
- Waivers
- ARC Family Resources
- Utility programs
- Social service agencies
- SSI
Considerations for provision of comprehensive care:
Oral health Issues

• Has an oral health care provider been identified?
• Are oral health risk assessments available in the pediatric primary care setting?
• Are medical home providers familiar with billing codes for oral health assessments?
• What referral procedures are in place after conducting oral health assessment?
• What resources are available to discuss dietary practices, fluoride exposure, oral hygiene, and the establishment of a consistent oral health care provider with families?
Community resources & agencies: Oral health

- Community dentists
- State Medicaid; SCHIP; Title V programs (some include oral health)
- Dental schools
Section Four: The Role of the Community in Providing Collaborative Care
Strategies for effective collaboration

- Develop an advisory team to review office procedures
- Collect feedback
  - Suggestion box
  - Quarterly office meetings that are open to families and YSHCN
  - Email-list that families/YSHCN can enroll
- Have mutual respect for everyone’s expertise and role in caring for the child
  - Include family representatives in office orientation for staff and new families
  - Provide education opportunities for staff to learn about the family perspective and collaboration skills
Strategies for effective interagency collaboration

- Identify community partners
- Identify ways to communicate among partners
- Identify barriers and opportunities for systems’ improvement
- Develop an implementation plan
  - What changes to be made?
  - Who will be responsible for which change?
  - Who will be affected by the changes?
  - How will others be educated about the changes?
  - How will the changes be evaluated?
- Have community-based agency representative(s) visit during a staff meeting
Strategies for continuous collaboration

• Keep communication honest, direct and to the point; avoid repetition
• Be open to change
• Commit to the collaborative goals set by all involved
• Identify appropriate method to facilitate on-going communication: Web site; newsletter; email-list; quarterly meetings
Section Five: Case Study

Tanya, Zach and Jennifer
Background of Family

• Mother, Tanya, is 17-yrs.
  - Single; senior in high school
  - Lives in metropolitan area
  - Has intact family (mother, father, sibling)
  - Average scholastic ability; labels herself as “an underachiever”
  - Does not qualify for family insurance; will for Medicaid

• Father, Zach, is several years older
  - Not in school
  - Not committed to “providing for his family”
At Birth

- Daughter, Jennifer, born and diagnosed with Down Syndrome
- Jennifer spends 1-mth in hospital due to congenital disease secondary to DS-GI
- Jennifer requires ongoing medication and assisted feedings
Current Situation

• Jennifer is now 4-yrs.; in pre-school
  - Shows developmental delays
  - Has nutritional issues secondary GI/Cardio disease
  - Significant language delay; nonverbal on indication

• Tanya is 21-yrs.; has her GED
  - Balancing school/job/childcare
  - Dependent on public assistance, transportation and educational grant
  - No support from Zach
  - Family lends psychological support, but physically removed
Discussion Questions

• What community resources will you help this family access?
• What federal/state regulations apply to the child and mother at this time?
• What is the role of the medical home in sharing information with this family?
• What procedures should be established for the medical home to follow up on information/resources shared with Tanya?
• What procedures could be put in place to keep the physician and office staff aware of community resources?
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