Duke Clinical Research Institute

Medical Home Manuscript from the Subcommittee on Follow-up and Treatment

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Motion for Committee Action

- Title of report: "**Family-Centered Coordinated Co-management for Individuals with Heritable Conditions**"

- Nature of support requested: **SACHDNC Acknowledgment**

- Request that the AC review and acknowledge the enhanced description of the medical home and strategies for improving linkage to the medical home for children with heritable disorders. No Formal actions requested of the Secretary or the Advisory Committee.

Medical Home Workgroup of the NCC

- **W. Carl Cooley, MD (Chair)**
- Sondra Gilbert
- Tamara Hartsnell, ARNP
- Matt Hirschfeld, MD
- Louise Kido Iwaishi, MD
- Alex Kemper, MD
- Marie Mann, MD
- Chuck Norlin, MD
- Robert Ostrander, MD
- Laura Pickler, MD
- Gregory Prazar, MD
- Brad Thompson
- Jane Turner, MD
- Mike Watson, PhD

Background

- In the 1990s, the medical home model emerged as a way of ensuring care for children with special health care needs that is
  - *Comprehensive*
  - *Coordinated*
  - *Family-centered*
- Increased recognition that this approach may be beneficial for all
- Various definitions

Primary Care

- Active coordination
- Co-Management
  - *Vertically within the health care system*
  - *Horizontally among community-based organizations and resources*

Key Stakeholders

- Families
- Primary Care
  - *In rare circumstances, a specialty clinic or special program may provide a medical home for a defined population for some period of time. To do so, must be:*
    - Comprehensive
    - Longitudinal
    - Coordinated
    - Accept first-contact responsibility for preventive, acute, and chronic care
- Specialty Care Team

Care Coordination

- Patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families
- Care coordination addresses interrelated medical, social, development, behavior, educational, and financial needs

Locus of Management

- Explicit identification of a lead clinical manager or management team and their scope of responsiblities
- Shifts over time, reflecting acuity, complexity, severity of health care needs

Planned Co-Management

- Proactive, anticipatory approach to care related to responsibilities within their expertise and the capacities in which they work
- Involves
  - *Structures (e.g., care plans)*
  - *Processes (e.g., communication)*
  - *Active input*
- Often requires dedicated personnel responsible for co-management plans
- Must have the endorsement and engagement of families

Health Care Transitions

- To Long-Term Follow-up
- From Hospitalization
- To Adulthood

Recommendations

1. Identify innovative programs, including care planning and tools that address co-management
2. Incorporate care planning, co-management, and family access functions into electronic health records and related information systems
3. Systematically evaluate preferences, concerns, and needs
4. Promote outcomes-based research
5. Training
6. Develop methods to incentivize medical home services

Questions?