Heartland Genetics and Newborn Screening Collaborative

TRANSITION SERVICES

Heartland Regional Meeting (2009) Roundtable Discussion

- Need Adult providers and specialists
- Build capacity for adult disorders
- Need coordinated care for adults
- Use of telemedicine for nutrition counseling and SC consultation
- Establish medical protocol for adult care
- Address comfort level of youth in moving to an adult care provider
- Other (pilot study, youth advocacy, reimbursement etc)

What is the role of the Heartland Collaborative in improving and providing access to transition Services for CYSHCN with heritable conditions?

Health Care Transition

The process of change from child and family centered health care to adult care requiring ongoing attention and planning, especially for youth.

Surveys and Recommendations related to transition of YCSHCN

- Surveys of families with YSHCN
- Small surveys of adults with PKU
- Surveys of adult health care providers
- Healthy People 2010 MCHB
- Recommendations (AAP, Society of Adolescent Med. etc)

COMMUNICATION AND COORDINATION

- 46% of adult providers rarely or never communicated with the previous health care provider.
- 57% of adult providers rarely or never received a written transfer summary from the previous provider.
- 48% of adult providers thought that youth/young adults entering their practices had experienced a gap between pediatric and adult care.

National Survey of Adult Health Care Providers about medical transition for YSCN (New Hampshire 2008)

BARRIERS TO CARING FOR YSHCN

- Lack of time, inadequate staffing, reimbursement issues
- Inadequate support from knowledgeable specialists who were sometimes perceived as barriers.

National Survey of Adult Health Care Providers about medical transition for YSCN (New Hampshire 2008)

PROVIDER COMFORT LEVEL

Most comfortable treating:

asthma (92%),
hypertension (89%)
intellectual disabilities (75%)

Least comfortable Treating

cystic fibrosis (15%)
chromosomal/metabolic disorders (14%)
Technology dependent (11%)

National Survey of Adult Health Care Providers about medical transition for YSCN (New Hampshire 2008)

Transition Activities

- New England Genetics Collaborative
- NYMAC (Region 2)
- MSRGC (Region 6)
- Regions 3, 4, and 7

New England Genetics Collaborative

- Collaboration of transition and medical home work groups
- Survey of primary care providers and pediatricians
- PKU tool kit distribution
- Survey of adult patients with metabolic conditions
- Development of other transition tools/instruments
- Survey of regional activities

NYMAC (Region 2)

- National metabolic and genetic conditions interegional Transition Workgroup
- Mini grants for implementation of PKU transition videos
- RFP for two transition projects to hire navigators
- Development of forms for protecting parental guardianship for adult children

MSRGC (Region 6)

- Funding pilot intervention using existing resources to support a demonstration model for successful transition.
- Model is focused on relationship between medical home and transition
- Goal is develop tools that can be used in other settings.

Regions 3, 4, and 7

- Development of survey tools for PKU and SC
- Development of listing or guidance
- Development of care templates
- Disseminating transition information
- Identifying strategies to develop a system approach to promoting transition
- Other

Common Themes

- Focus on PKU
- Development of templates and care plans
- Relationship between medical home (PCPs') and Transition

HRSA D-70

State Implementation Grants

for

Integrated Community Systems

for CSHCN

D-70 Colleagues

- George Gotto (Mo)
- Mary Ann Bechtold (KS)
- Wendy Parent (KS)
- Heather Moore (KS)

Transition Services

A coordinated set of activities for an individual with a disability that supports integration from adult health care providers and obtaining knowledge and competencies about adult related services within the medical, school to post school activities, vocational training, integrated employment, continuing and adult education, adult services, independent living, and/or community participation.

Topeka meeting
4/21/10

- Develop a transition model within the medical home
- Hold a regional conference of stakeholders related to transition

What's Next for Heartland?

Heartland Transition Work Group

Mary Ann Bechtold (KS)
Jo Ann Bolick (AR)
George Gotto (MO)
Tamara Hartsell (OK)
Holly Johnson (AR)
Barbara Khal (IA)
Debbie Kloker (OK)
Donna LeBlanc (AR)
Heather Moore (KS)
Wendy Parent (KS)
Dawn Peck (MO)
Kim Piper (IA)
Brad Schaefer (AR)
Mark Smith (NE)
Sharon Vaz (OK)
Ralph Vogel (AR)
Debra Waldron (IA)
Linda Williams (KS)

Proposed Transition Activities for Heartland

- Pilot Project
- Survey?
- Stakeholder Conference?

National Health Care Transition Center

Opening Doors to a Healthy Future

PI: W. Carl Cooley, MD

The NHCTC will assure that youth with and without special health care needs receive care in a medical home providing family-centered/youth activated preparation and planned transitions from pediatric to adult health care that are respectful of all social determents of good health.

National Medical Home Workgroup of the National Coordinating Center of the regional genetics and newborn screening collaborative

- Define necessary functions of medical home
- Examine the effective tools for communication and co management
- Consider means of tracking and measuring co management best practice