Newborn Screening, Long-Term Follow-Up, and Medical Home: Is Integration Possible?

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AAP Project Advisory Committee, MH Initiatives
December, 2006
Every System is Perfectly Designed to Get the Results it Gets

- Institute for Healthcare Improvement
- National Initiative for Children’s Healthcare Quality
Definition of Medical Home

- Care that is:
  - Accessible
  - Family-centered
  - Comprehensive
  - Continuous
  - Coordinated
  - Compassionate
  - Culturally-effective
Definition of Medical Home

- And for which the primary care provider shares responsibility with the family.

AAP/ AAFP/ NAPNAP/ ACP
Functional Definition of Medical Home

- Partnership between family and providers
- Commitment to continuous quality assessment and improvement
- Single point of entry to a “system” of care that facilitates access to medical and non-medical resources
What Do Families Say a Medical Home Is?
Medical Home

- It is an “Attitude”.
- Care Coordination addressing medical as well as non-medical issues.
- Referrals to specialists who embrace similar philosophies.
- Parent-Professional Partnership.

Parent Advisory Group, Nashaway Pediatrics
Care Model for Child Health in a Medical Home

Adapted from Wagner, et al

Community
Resources and Policies

Health System
Health Care Organization (Medical Home)
- Care Partnership Support
- Delivery System Design
- Decision Support
- Clinical Information Systems

Supportive, Integrated Community
- Family-centered

Informed, Activated Patient/Family
- Timely & efficient
- Evidence-based & safe

Prepared, Proactive Practice Team
- Coordinated and Equitable

Functional and Clinical Outcomes

NICHQ
Community of Care Model
Building MH Systems

Family to Family Supports

Educational Systems:
- Birth to 22 Years

Quality Advocates
Leapfrog, NQF

Title V
- PCOC
- AAP/AAFP
- NAPNAP/ACP

Antonelli AHRQ Conf, 2002

Pediatric PCP’s and specialists
- Including mental health
- Adult PCP’s and specialists and transition advisors

State and Federal Agencies
- MCO’s
  - public/private
  - Employers/Purchasers

CSHCN, YSHCN and Family

CBO’s
- Grantsmakers

2006
“Current care systems cannot do the job. Trying harder will not work. Changing systems of care will.”
Priority Areas for National Action: Transforming Health Care Quality

- Priorities Relating to Children and Youth
  - Care Coordination- across paradigms of care
  - Self-management/ health literacy
  - CYSHCN
  - Immunizations
  - Depression
  - Medication Management
Chain of Effect Framework
(Berwick, Health Affairs, 2002)

- Level A: experience of patients
- Level B: “microsystems” (eg, the team that provides the care)
  - Knowledge-based care
  - Patient-centered care
  - Systems-minded care (emphasis on coordination of care; chronic condition management)
Chain of Effect Framework
(Berwick, Health Affairs, 2002) continued

- Level C: Health care organizations
  - Finding and adopting evidence-based, best practices
  - IT
  - Education of staff
  - Coordination of care across settings
  - Outcome and performance assessment
Chain of Effect Framework
(Berwick, Health Affairs, 2002) continued

- **Level D:** health care environment
  - Policy
  - Reimbursement
  - Regulation
  - Accreditation
  - Etc.
1/3 of US patients with health problems had experienced medical errors. Americans were more likely to experience inefficient coordination of care, and high out-of-pocket expenses deterring them from seeking treatment for chronic diseases compared to other developed countries.

Commonwealth Fund, Health Affairs, Nov 2005
What is Care Coordination?

A process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health.

AAP 2005
Stakeholders

- Families
- Employers (Leapfrog Group, National Quality Forum)
- Providers
- Community-Based Organizations
- Payers: Medicaid and Commercial
- State and Federal Agencies
- Legislators
Metanoia: Thinking About Medical Outcomes: Results-Based Accountability (Friedman)

- Born Optimally Healthy
- Healthy and Developing Well
- Healthy and Ready to Learn (school entry)
- Healthy and Ready to Work (adolescence into young adulthood)
Comments from the “Trenches” of Primary Care Across the US about NBS, LTFU, and Medical Home

- In some regions, referral across state lines is possible
- Problems with CC in MH are NOT unique to metabolic and genetic conditions; they apply to any chronic conditions
- Even when some services available (eg, metabolism SP), allied services (eg, nutrition) not linked
Comments from the Trenches

- Ensure prenatally identified PCP in MH
- Reimburse for the visit (consider it a standard of care) with agenda to include NBS and options for outcomes
- Develop care coordination as a discipline, linked to MH
What Needs to Be Done Now?

Choose an Option:

- NBS program requires multiple paradigms for F/U that are diagnosis specific
- Integrated model that builds on the strength of MH and collaborative, coordinated care

Guess which one I recommend?
Integrated, Coordinated MH Model of Care for NBS and LTFU

- What are the barriers?
## Barriers to Care Coordination

**AAP Periodic Survey #44**  
August 2000

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Coordinator</td>
<td>71%</td>
<td>5%</td>
<td>Time</td>
<td>Staff</td>
<td>Time</td>
<td>Communic.</td>
<td>Time</td>
<td>Reimburs.</td>
</tr>
<tr>
<td>Discuss non-medical needs</td>
<td>41%</td>
<td>14%</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Assist with discharge plan</td>
<td>24%</td>
<td>41%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact with school</td>
<td>24%</td>
<td>16%</td>
<td>Time</td>
<td>Communic.</td>
<td></td>
<td></td>
<td>Time</td>
<td>Reimburs.</td>
</tr>
<tr>
<td>Post-specialist appointment</td>
<td>19%</td>
<td>28%</td>
<td>Time</td>
<td>Reimburs.</td>
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</table>
What Are Barriers to NBS and LTFU and Coordination in MH?

- Technical Knowledge and Skills of Providers
- Definition and Role Responsibility
  - Who will coordinate care across systems?
- Availability of Resources (for consultation, support, long term management)
What Are the Opportunities?

- Care Coordination (CC) that is evidence-based and reimbursed and available directly to families at the community and MH level
- CC that is auditable and integrated as a standard of care (eg, use of written care plans)
What Are Facilitators?

- P4P
- Bright Futures
- Develop Chronic Condition Management in MH
Mechanism for Shared Care

- Co-Management: evidence-based to enhance access
- Distinguish from consultative model since it emphasizes mutual education, shared and delineated responsibilities
- Optimizes utilization of subspecialist (SP) resources
- Reimburses both PCP and SP
- CC is reimbursed
- Builds on existing relationships
- Enhanced access and sustainability are goals
What About Transition into Adulthood for Youth with SHCN?
The Ultimate Outcome: Transition to Adulthood

Health Care Transition Requires Time & Skills for children, youth, families and their Doctors too!
## How Many CYSHCN?

13-40% of Pediatric Population in US

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
<th>Age Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>9.4 million</td>
<td>(13%) &lt;18</td>
</tr>
<tr>
<td>Title V CYSHCN</td>
<td>963,634</td>
<td>0-18*</td>
</tr>
<tr>
<td>SSI Recipients</td>
<td>1,036,990</td>
<td>0-17</td>
</tr>
<tr>
<td></td>
<td>386,360</td>
<td>13-17</td>
</tr>
</tbody>
</table>

Sources:
1. www.cshcndata.org
   * Most State Title V CSHCN Programs end at age 18
Outcome Realities

- 90% of YSHCN reach their 21st birthday

- Nearly 40% cannot identify a primary care physician

- 20% consider their pediatric specialist to be their ‘regular’ physician

- Significant numbers have extensive primary health concerns that are not being met

- Fewer work opportunities, lower high school grad rates and high drop out from college

CHOICES Survey, 1997; NOD/ Harris Poll, 2000; KY TEACH, 2002
Outcome Realities

- YSHCN are 3 times more likely to live on income under $15,000

- The National Survey of CSHCN, 2001 revealed that only 6.3% of YSHCN ages 13-17 perceived they had received preparation for transition to adulthood.

- 35% of 18 – 24 year-olds lack a payment source for health care

CHOICES Survey, 1997; NOD/Harris Poll, 2000; KY TEACH, 2002
Percent Uninsured by Age:
People under age 65, first half of 2002
Center for Cost and Financing Studies, AHRQ, Medical Expenditure Panel survey,
2002 Point-in-time File
What is the System Level Problem?

It’s the Culture and Design of the System!!
<table>
<thead>
<tr>
<th><strong>Issue</strong> (White, adapted from Rosen)</th>
<th><strong>Pediatric</strong></th>
<th><strong>Adult</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age-related</td>
<td>Growth &amp; development, future focussed</td>
<td>Maintenance/decline: Optimize the present</td>
</tr>
<tr>
<td><strong>Focus</strong></td>
<td><strong>Family</strong></td>
<td><strong>Individual</strong></td>
</tr>
<tr>
<td><strong>Approach</strong></td>
<td>Paternalistic Proactive</td>
<td>Collaborative Reactive</td>
</tr>
<tr>
<td><strong>Shared decision-making</strong></td>
<td>With parent</td>
<td>With patient</td>
</tr>
<tr>
<td><strong>Management</strong></td>
<td>Prescriptive</td>
<td>Collaborative</td>
</tr>
<tr>
<td><strong>Non-adherence</strong></td>
<td>&gt; Assistance</td>
<td>&lt; Tolerance</td>
</tr>
<tr>
<td>Procedural Pain</td>
<td>Lower threshold of active input</td>
<td>Higher threshold for active input</td>
</tr>
<tr>
<td>Tolerance of immaturity</td>
<td>Higher</td>
<td>Lower</td>
</tr>
<tr>
<td><strong>Coordination with federal systems</strong></td>
<td>Greater interface with education</td>
<td>Greater interface with employment</td>
</tr>
<tr>
<td>Care provision</td>
<td>Interdisciplinary</td>
<td>Multidisciplinary</td>
</tr>
</tbody>
</table>
## Shared Decision Making

Adapted by P. White, from G. Kieckhefer, 2005

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent/Family</th>
<th>Young Person</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Major responsibility</strong></td>
<td>Provides care</td>
<td>Receives care</td>
</tr>
<tr>
<td>Support to parent/family and child/youth</td>
<td>Manages</td>
<td>Participates</td>
</tr>
<tr>
<td>Consultant</td>
<td>Supervisor</td>
<td>Manager</td>
</tr>
<tr>
<td>Resource</td>
<td>Consultant</td>
<td>Supervisor</td>
</tr>
</tbody>
</table>
Providers’ Self-Rating of Transition Processes

04% Not interested

25% No processes, but interested

32% Beginning stages

18% Working on; about halfway to where want to be

11% Have transition policy and processes integrated into practice
Models for Transition of Health Care

- **Co-Management between primary care and subspecialists** (both pediatric & adult neph):
  - shared letters
  - shared visits
Models for Transition of Health Care

- CME opportunities

- Encourage patient “get acquainted visits with adult providers”

- Facilitation by physicians, nursing or office staff, care coordinators, and youth themselves
Transition to Adulthood
Useful Websites for Medical Home

- http://www.medicalhomeinfo.org: American Academy of Pediatrics hosted site that provides many useful tools and resources for families and providers
- http://www.medicalhomeimprovement.org: tools for assessing and improving quality of care delivery, including the Medical Home Index, and Medical Home Family Index
References for MH and CC

- U.S. Department of HHS, New Freedom Initiative. [www.hhs.gov/newfreedom](http://www.hhs.gov/newfreedom)


Antonelli, R., Stille, C. and Freeman, L., Enhancing Collaboration Between Primary and Subspecialty Care Providers for CYSHCN, Georgetown Univ. Center for Child and Human Development, 2005
Other Evidence that CC Makes an Impact

- Reduction in Neonatal Intensive Care Unit Admission Rates in a Medicaid Managed Care Program Stankaitis, et al. Amer J Man Care, March, 2005

- Use of Asthma Guidelines by PCP’s to Reduce Hospitalizations and ED Visits in Poor, Minority, Urban Children, Cloutier, M, Hall, C, Wakefield, D, Bailit, H. J Pediatrics, 2005
Resources: Transition

HRSA/MCHB funded National Centers (6)

1. HEALTH & TRANSITION  www.hrtw.org
   Healthy & Ready to Work National Resource Center

2. MEDICAL HOME  www.medicalhomeinfo.org
   National Center on Medical Home Initiatives

3. FAMILY PARTNERSHIP  www.familyvoices.org
   National Center on Family and Professional Partnerships
Resources: Transition

HRSA/MCHB funded National Centers (6)

4. CULTURAL COMPETENCE

http://www11.georgetown.edu/research/gucchd/nccc/

National Center for Cultural Competence

5. HEALTH INSURANCE

http://www.hdwg.org/cc/

Catalyst Center – for Improving Financing of Care for CYSHCN

6. DATA

www.cshcndata.org

Data Resource Center National Survey for CYSHCN
Resources: Transition

HEALTHY & READY TO WORK  www.hrtw.org

- **HRTW Portable Medical Summary** - One page summary of health needs that youth or others can carry. Information contains medical history, current medication, name of health surrogate, health insurance numbers, contact information for treating doctors, pharmacy, home health and other vendors.

- **Understanding Health Insurance** - Web links to Choosing a Plan, Paying for Care, Public Insurance, Private Insurance, Policy / Advocacy Centers and Insurance Regulations, Laws and Statutes.

Resources: Transition

HRTW Portal - Laws that Affect CYSHCN
http://www.hrtw.org/tools/laws_leg.html

The Term Special Health Care Needs or Disability

Disability Rights Portals

Education Issues

Employment & Disability

Equal Opportunity Access (504, 508 & ADA)

Family Medical Leave Act

HRSA/MCHB – Title V Legislation

Health Insurance Benefits

SSI/SSDI
Resources: Transition

ADOLESCENT HEALTH TRANSITION PROJECT
Washington

http://depts.washington.edu/healthtr/index.html

- **Transition Timeline for Children and Adolescents with Special Health Care Needs.** Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go of others. The Timeline for Children may help you think about the future.

- **Working Together for Successful Transition:** Washington State Adolescent Transition Resource Notebook - Great example to replicate.

- **Adolescent Autonomy Checklists**
HEALTH AND HEALTHCARE IN SCHOOLS
The Impact of FERPA and HIPAA on Privacy Protections for Health Information at School. Sampling of the questions from school nurses and teachers.

NICHCY - National Dissemination Center for Children with Disabilities  www.nichcy.org
Materials for families and providers on: IDEA, Related Services and education issues – in English/Spanish

Section 504 http://www.ed.gov/about/offices/list/ocr/504faq.html