Transi'oning through Life
Stages: Growing up with a
Special Health Need

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Metabolic Diseases Today

• 300-1500 known Inborn Errors of Metabolism
• 50 % of them have been discovered in the last 25 years and more continue to be discovered
• Incidence of 1:4000 live births
  (1000 live births/year)
• Metabolic disorders are a major cause of chronic illness in childhood
Impact Inherited Metabolic Disorders

- Account for 5-6% of SIDS cases
- Require Life-long care!
- Now reaching Childbearing Age
- Increased Maternal risk of HELLP syndrome or Fatty Liver of Pregnancy
- Adult Sequelae - Learning problems, Vision loss, Cardiomyopathy, Peripheral Neuropathy, Chronic Liver disease (?), Depression & Anxiety disorders, pregnancy

Impact Inherited Metabolic Disorders

- Children with metabolic disorders are hospitalized 3-4 times more often than other children
- Account for 12% of Pediatric Admissions (50% of Pediatric Admissions have a Genetic Disease)
- Account for 55% of overnight stays
- Increase LOS on average of 3 days
- Incur 184% of Inpatient costs
- 4-5% higher in hospital mortality rates
- 40% of overall Childhood mortality related to Genetic diseases
Importance of Definitive Care

- Costly, poor outcomes when not treated
- Collectively, not that rare
- More and more are treatable
- Full characterization can be used for future Prenatal Diagnosis
- Provides opportunity to future care planning

A team is needed to raise these children

- Parents/other family members
- PCP – Medical Home
- Metabolic Team
- PT, OT, SLP (local Early Intervention team)
- Developmental Pediatrician
- Gastroenterology
- Cardiology
- Ophthalmology
- Neurology
- Transplant Team
- Special needs Dentist
- Pharmacist/Medical Supply company
How did we get started?

- Olmstead Act of 1999 operationalized Americans with Disability Act 1990 (ADA)
  - “reasonable efforts” by States
- Presidents New Freedom Initiative 2001
  - Increased assistive technology access
  - Increased educational opportunities
  - Promoted home ownership/community involvement
  - Encouraged “integrated” workforce
  - Increased transportation options

How did we get started?

- Surgeon General’s “Call to Action” 2005
  - Assess trajectory of disabilities
  - Increase knowledge of Healthcare providers
  - Supported self-management & health promotion
  - Increased Healthcare & Social Services access
How did we get started?

• President Bush’s Executive order February 2008
  – Implement strategies to improve health of American youth including encouraging Inter-agency cooperation and improved community-based resources
  – Encouraged development of youth oriented websites & support groups.

Maternal and Child Health Bureau (1998)

Define Children with Special Health Needs as:

“Those children who have or at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type or amount beyond that required by children generally.”
Healthy People 2010 Goals

- Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive.
- Children and youth with special health care needs receive coordinated, ongoing comprehensive care within a medical home.
- Families of CBHCs have adequate private and/or public insurance to pay for the services they need.
- Children are screened early and continuously for special health care needs.
- Community-based services for children and youth with special health care needs are organized so families can use them easily.
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Maternal and Child Health Bureau

- Charged with providing services since 1935 through Title V of the Social Security Act
- 2004 Transitional Care became 1 of 6 Core Outcomes:

  “Youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.”
Scope of the Problem

- 54 million people or 20% of the U.S. population
- 12 million children in the U.S.
- Costs $300 billion annually or 4% of the gross domestic product
- 50% of the cost is related to medical expenses
- 50% of the cost is related to lost productivity
- For the total population with disabilities there is an increased risk for secondary health problems due to lack of regular health promotion & screening.

Scope of the Problem

- 60% male
- 68% Non-Hispanic white
- 45% have “Medical Home” resources
- 84% have normal activities disrupted
- 42% have thought about shifting care
- 62% have “some knowledge” of anticipated health problems
- 34% have some knowledge of insurance issues
Scope of the Problem

- 78% of children with special health needs are encouraged to take responsibility for their own care
- Non-English speaking, low-income are at greatest risk of not making successful transition
- Most significantly impacted by special health need also at risk for unsuccessful transitions
- Females more likely than males to have successful transitions
### Percent of CSHCN Needing Specific Health Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescription drugs</td>
<td>86.4%</td>
</tr>
<tr>
<td>Preventive dental care</td>
<td>81.1%</td>
</tr>
<tr>
<td>Routine preventive care</td>
<td>77.9%</td>
</tr>
<tr>
<td>Specialty care</td>
<td>51.8%</td>
</tr>
<tr>
<td>Eyeglasses/vision care</td>
<td>33.3%</td>
</tr>
<tr>
<td>Mental health care</td>
<td>25.0%</td>
</tr>
<tr>
<td>Other dental care</td>
<td>24.2%</td>
</tr>
<tr>
<td>Physical, occupational, or speech therapy</td>
<td>22.9%</td>
</tr>
<tr>
<td>Disposable medical supplies</td>
<td>18.6%</td>
</tr>
<tr>
<td>Durable medical equipment</td>
<td>11.4%</td>
</tr>
<tr>
<td>Hearing aids/hearing care</td>
<td>4.7%</td>
</tr>
<tr>
<td>Home health care</td>
<td>4.5%</td>
</tr>
<tr>
<td>Mobility aids/devices</td>
<td>4.4%</td>
</tr>
<tr>
<td>Substance abuse treatment</td>
<td>2.8%</td>
</tr>
<tr>
<td>Communication aids/devices</td>
<td>2.2%</td>
</tr>
</tbody>
</table>

### Receipt of Coordinated Care: CSHCN

- Locked one or more elements of coordinated care: 31.8%
- Received coordinated care: 46.0%
- Did not need coordinated care: 22.2%

### Percent of CSHCN Whose Care Did Not Meet Individual Care Coordination Components

- Communication among health care providers: 23.7%
- Receipt of help coordinating care: 14.7%
- Communication between health care providers and other providers/programs: 12.9%
Considerations

• Assume responsibility for personal care
• Anticipate future health needs
• Obtain future healthcare providers
• Plan for Health Insurance changes
PCP – Medical Home

- Patient Safety
- Effectiveness*
- Efficiency
- Family-Provider Partnership*
- Health Status*
- Timeliness*
- Equity
- Cost*

PCP – Medical Home

- Effectiveness
  - Adherence to plan of care (medications, diet)
  - Fewer hospitalizations and/or decreased length of stay
  - Fewer ED visits
- Family-Provider Partnership
  - Increased Self management
  - Improved Satisfaction
  - Decreased Family stress/improved Family functioning
- Health Status
  - Fewer School or Work days missed
  - Fewer unmet needs
PCP – Medical Home

• Timeliness
  – Less time to have phone calls returned
  – Less time to get an appointment
  – Same day appointment availability
  – Access to Provider after hours

• Cost
  – Decreased Short-term costs
  – Decreased Long-term costs

The Hand-off:
Goal is a seamless hand-off

• Traditional separation of Pediatric and Adult care
• Internal Medicine specialists most comfortable with disorders they see in Adult patients already: Diabetes, Obesity, Cancer, Intellectual disability etc...
• Lack of preparation at the receiving end
• Lack of knowledge at the hand-off end
The Hand-off:
Goal is a seamless hand-off

- Emotional Rapport between Pediatric Providers & families is a strength & weakness
- Reimbursement and Administrative Barriers to Co-management
- Models exist:
  - Geriatric-End of Life Case Management
  - Childhood Cancer Survivor care
  - Cystic Fibrosis
  - Congenital Heart Disease

Insurance Concerns:
Goal is continuous, uninterrupted coverage

- Life-time caps of expenditures
- Confusion about coverage since some private insurers cover children still in school until 22 years of age
- Medicaid Waivers end at 18 years of age
- SSI/Disability can start at 18 years of age
New Insurance Trends:

• “Ticket to Work” Programs
  – Meet SSI criteria, able to work however not able to make sufficient pay to meet needs

• Adult Disabled Dependent Child clauses
  – Must prove life-long disability
  – No ability for substantial gainful employment
  – Requires annual recertification

• Court ordered benefits
  – Need time-frame specified

New Insurance Trends:

• Raising the Age of dependency
  – Applies to single children without children of their own
  – 24 years in DE, IN & SD*
  – 25 years in CO, ID, ME, MD, MT, NM, RI, TX, VA, WA, WV
  – 26 years in CT, MA, NH, UT
  – 30 years in NJ, SD with Employer support*
  – PENDING laws in AK, CA, FL, MN, MO, NV, NY, PA, OH, TN
What is needed?

- Children with Special Health Care needs
- Parents/Guardianship
- PCP (Medical Home)
- Current Specialists
- Professional Organizations
- State & Federal Resources

Role of Child with the Special Health Need

- Be aware of Age of Majority
- Learn about their health care needs
- Actively participate in keeping themselves healthy
- Acquire necessary skills to implement the health care plan
- Become their own advocate
- Be able to obtain all necessary services
Parents Role

Teach, encourage as we do with every other transition

– Call for an appointment, lab test or to refill a medication
– Arrange transportation
– Know Medications & dosages like you know your address & phone number
– Dispense medications, mix formulas, cook meal for the family, make lunch for school or work
– Discuss sexuality & pregnancy
– Have an emergency plan in place

Birth to Three

• Develop trust
• Take breaks to maintain your energy & health
• Begin record keeping of early childhood interventions, medical history, surgeries and injuries, immunizations, medications, special diets, allergies & adverse drug events
• Create list of Specialists involved in your child’s care
• Apply for Medicaid Waiver whenever possible
Three to Five

- Develop decision-making skills by offering choices
- Encourage participation in household chores
- Get involved in recreational & community activities
- Begin to teach self-care related to chronic illness
- Encourage interaction with therapists, nurses & doctors
- Begin teaching about personal space & relationships
- “What do you want to do when you grow up?”

Six to Eleven

- Strengthen knowledge of chronic illness
- Strengthen self-care abilities
- Discuss personal safety
- Consider 504 Plan or IEP needs
- Encourage Hobbies & Leisure activities
- Begin shopping with the child
- Discuss consequences of poor choices
- Teach self-advocacy skills
Twelve to Eighteen

- Fill in gaps about special health needs
- Encourage self-care
- Include adolescent in 504 & IEP plans
- Support ordering their own medications & supplies, calling for appointments etc...
- Discuss sexuality
- Consider special needs Camp attendance
- Explore insurance changes
- Plan for Provider changes
After Eighteen

• Assume for responsibility for getting health needs met
• Parent should remain resource & social support
• Continue Hobbies & leisure activities
• Encourage Support Group involvement
• Connect to community-based or college-based disability services
• Consider contacting Department of Vocational Rehabilitation

Parents Role

Long-term Planning
  — Guardianship
  — IEP inclusion
  — Vocational training/other secondary education
  — Supervised Living Arrangements
  — Estate Planning
Barriers to the Medical Home and Transitional Care Movement

- Lack of Training
  - Specific conditions
  - Cultural Sensitivity
- Lack of Care Coordination Tools
- Lack of knowledge or access to Patient Registeries & Support organizations
- Lack of key personnel: Care Coordinator, Social Worker, Dietitian
- Time

Resources

- www.medicalhomeinfo.org
- www.familyvoices.org
- www.cms.hhs.gov/RealChoice/06_FamilytoFamily.asp
- www.socialsecurity.gov/disabilityresearch/youth.htm
- www.hdwg.org/cc
- http://depts.washington.edu/transmet
Directions:
Resources for Your Child’s Care


For information and to obtain this book, visit www.ct.gov/dph.
For Directions: Resources for Your Child’s Care, look under Publications.

GOING TO WORK
A Guide to Social Security Benefits and Employment for Young People with Disabilities

By Linda Levy-Belfi, Veronica Verteras, and Linda Lundy

2009 edition
It’s Time To Transition!

A Workbook for Young Adults, Their Families, and Their Medical Providers

Shared with Mountain States Regional Collaborative 2006