

Transitions: Growing up with a Special Health Need

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Undiagnosed Diseases program

Epi-743 MitoWorks trial

Congenital Disorders of Glycosylation

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Metabolic Diseases

- 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
- Long-term follow provides valuable natural history information that can be used to develop therapies

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

Maternal and Child Health Bureau (1998)

Defined 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.”

Olmstead Act of 1999

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

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

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

- 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.”

Patient Protection and Affordable Care Act (ACA) 2010

- Increased Access
 - No Pre-existing condition limitations for children under 19 years of age
 - No life-time caps
 - No caps on Out-of-pocket costs
 - Essential services now include Dental, Vision & Habitation
 - Dependent coverage up to 26 years of age

Patient Protection and Affordable Care Act (ACA) 2010

- Transforming Pediatric Health Care
 - Mandated Health Care teams which is critical to children with special health needs who need access to multi-disciplinary teams
 - Mandated access to Clinicians with expertise in Pediatrics

Scope of the Problem

- 54 million people or 20% of the U.S. population
- 12 million children in the U.S.
- Pediatric medical care costs \$300 billion annually or 4% of the gross domestic product (adult medical care \$2.4 trillion)
- 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 at greatest risk of not making successful transition
- Most significantly impacted by special health needs are also at risk for unsuccessful transitions
- Females more likely than males to have successful transitions



The Health and Well-Being of Children:

A Portrait of States and the Nation
2011-2012



June 2014

U.S. Department of Health and Human Services
Health Resources and Services Administration

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

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 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.childhealthdata.org/learn/NS-CSHCN
- http://www.medicalhomeinfo.org/how/care_delivery/cyshcn.aspx
- <http://www.cms.gov/>
- www.familyvoices.org
- <http://www.socialsecurity.gov/disabilityresearch/index.html>
- <http://hdwg.org/catalyst/>



Directions: Resources for Your Child's Care

Connecticut Edition, 2010

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

WorkWithoutLimits
Putting abilities to work in Massachusetts.

GOING TO WORK <<<<

A Guide to Social Security Benefits and Employment for Young People with Disabilities
2011 Edition • by Linda Long-Bellil, Melanie Jordan, and Linda Landry



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