

## Children with special health care needs:

Who they are and how we know whether we are serving them well

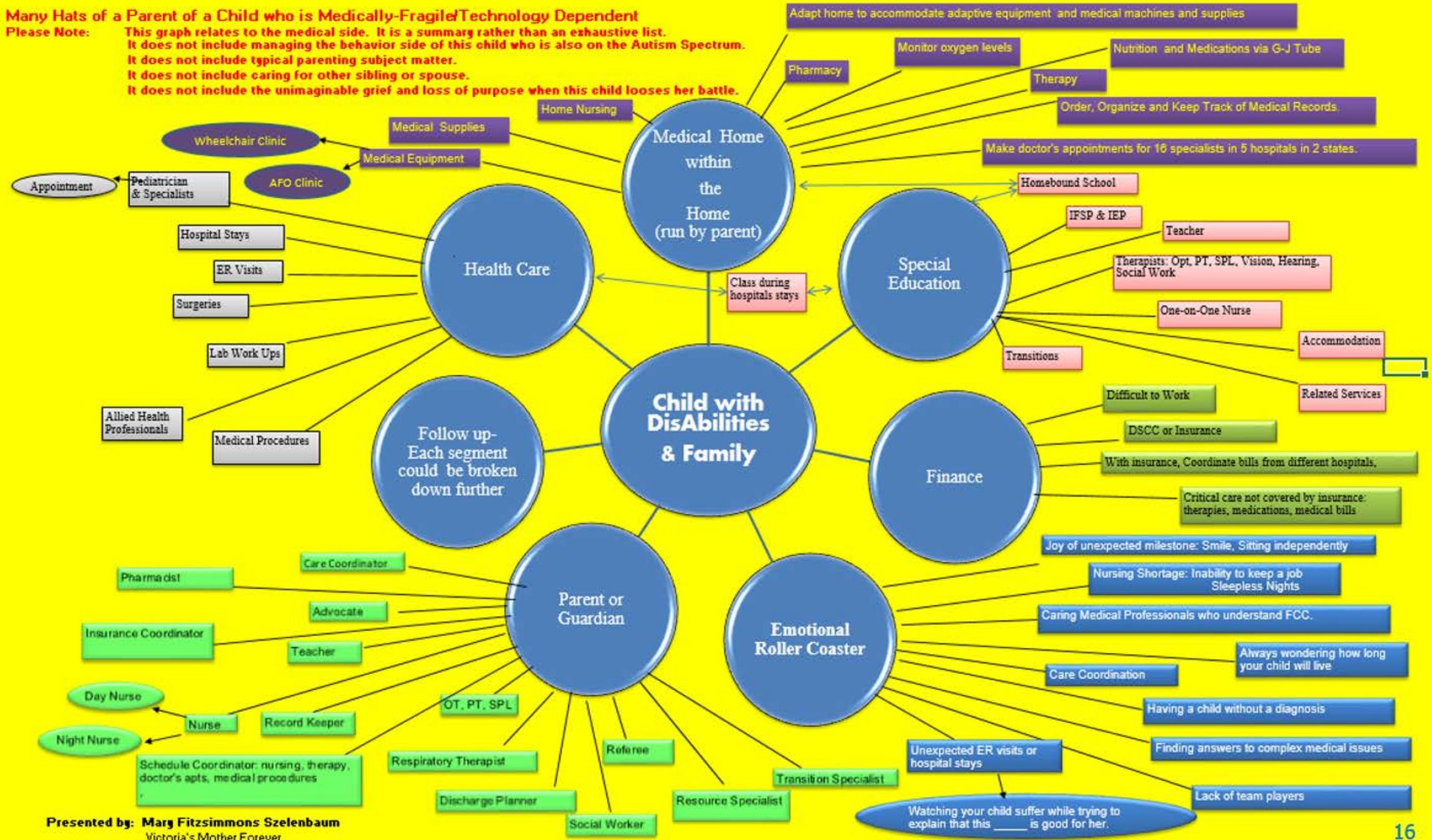
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# Many Hats of a Parent of a Child who is Medically-Fragile/Technology Dependent

**Please Note:** This graph relates to the medical side. It is a summary rather than an exhaustive list. It does not include managing the behavior side of this child who is also on the Autism Spectrum. It does not include typical parenting subject matter. It does not include caring for other sibling or spouse. It does not include the unimaginable grief and loss of purpose when this child loses her battle.



# Background

- The current healthcare system rarely addresses the medical needs of medically complex children and adolescents
- These children often do not get needed or timely outpatient services because of the disjointed nature of the healthcare system
- The lack of highly coordinated care puts the well-being of medically complex children at risk and uses very expensive disconnected services in a sub-optimal manner
- Costs associated with this population can be 7 times the average costs for the pediatric population

Who are children with special health care needs?

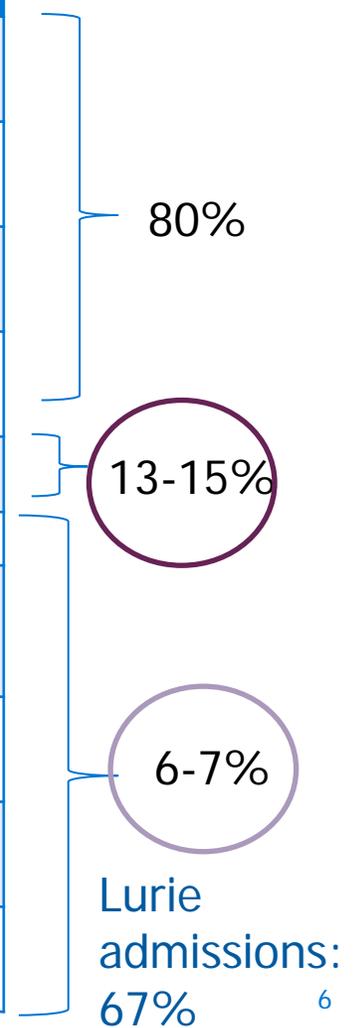


# Useful but confusing terms (unofficial definitions)

Term:	Used to describe children who require:	Examples:
Children with special needs	Educational, health care or other supports that are not typical	Autism, dyslexia, all health care needs
Children with special health care needs	Health services that are not typical (often also need educational supports)	Cerebral palsy, sickle cell, mental health conditions, epilepsy
Children who are medically fragile	Supportive technology	Some cerebral palsy, some epilepsies
Children with chronic conditions	Ongoing care (of any level)	Asthma, diabetes, cerebral palsy
Children with medical complexity	Care across many systems and medical specialties	Cancer, cerebral palsy, muscular dystrophy, some epilepsies, severe mental/emotional problems

# More precision (3M Clinical Risk Groupings):

CRG Status	Definition	Example
1	Healthy (no recent procedures or significant acute conditions)	Well child
2	Recent history of a significant acute disease	Recent significant injury
3	Single minor chronic disease	One condition - ADHD, excema, allergic rhinitis
4	Minor chronic disease(s) affecting multiple organ systems	More than one condition -ADHD, excema, allergic rhinitis
5a	Single dominant chronic disease	Asthma, obesity
5b	Single dominant chronic disease	Diabetes Type I, sickle cell
6	Significant chronic disease affecting multiple organ systems	Diabetes Type I with mental health problem, sickle cell with respiratory problem
7	Dominant chronic disease affecting three or more organ systems	Endocrine conditions
8	Dominant , metastatic and complicated malignancies	Cancer
9	Catastrophic and progressive conditions	Muscular dystrophy; transplants



How do we know if we are  
serving them well?



# Well-coordinated care saves costs and increases access to services

Service pattern to achieve savings is different than other populations.

Service	Cost Savings
Inpatient	-40%
Outpatient	+10%
Emergency Room	-20%
Primary Care Services	+30%
Prescription Drugs	+10%
Medical Cost Savings	-13% to -10%

Care coordination studies generally focus on the CRG 5b-9 group.

Studies of Lurie Children's efforts generally replicate findings from other, published studies.

# Well coordinated care assures access to needed services

Medical/health home indicators:	Private insurance	Medicaid/ public insurance
CSHCN has no usual source of sick and well care	7.6%	17.5%
CSHCN has no personal doctor or nurse	3.6%	10.1%
CSHCN receives family-driven care	74.8%	59.5%
CSHCN has problems getting a needed referral	18.4%	29.4%
CSHCN has care that meets all care coordination requirements	47.4%	41.0%

Source: 2009/10 National Survey of Children with Special Health Care Needs (Illinois)

# Well coordinated care provides integration across sectors

Indicators of cross-sector coordination	Private insurance	Medicaid/ public insurance
Difficulty/delayed in getting community-based services in last year	27.0%	33.8%
Never frustrated getting services in last year	73.2%	55.5%
Communication was needed between the physician and the school in the last 12 months	26.8%	38.7%
Very satisfied with the physician-school communication in the last year	56.5%	55.8%
CSHCN has an IEP	27.1%	33.9%

Source: 2009/10 National Survey of Children with Special Health Care Needs (Illinois)

Metrics relevant to children  
with special health care needs



# Proposed metrics

<b>Patient satisfaction surveys            (CAHPS survey for children            with chronic conditions)</b>	<b>HEDIS            (claims-based)</b>	<b>HFS            (claims-based)</b>
Access to and use of specialized services	Influenza immunization rate	Vision screening
Access to and use of prescription medication	Developmental screening in the first three years of life	Ambulatory follow-up after IP visit and ED visits
Family-centered care	Preventive dental services	
	Well child visits (through adolescence)	
	Lead screening	

Questions?