



A Conversation on Protecting Rights of Children with Medical Complexity in an Era of Spending Reduction

September 20, 2018



Moderator

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PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

MARCH 2018 • VOLUME 141 • SUPPLEMENT 3

A SUPPLEMENT TO PEDIATRICS

Building Systems That Work for Children With Complex Health
Care Needs

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Sponsored by the Lucile Packard Foundation for Children's Health.

*Based on follow-up from a symposium held December 7–8, 2015, Washington,
District of Columbia.*



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Ask Questions!

We look forward to a lively discussion with our audience.
Enter questions in the GoToWebinar question box.

Meet Our Speakers



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Children's Health

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Opening the Conversation

- Overview of Child Status
- Importance of Insurance Coverage
 - Private Insurance
 - Medicaid
- Importance of Enforcement

Private Insurance

(employer-sponsored, individual, ACA marketplace)

- Affordable Care Act Essential Health Benefits
 - Pediatric oral & vision; rehabilitation & habilitation
- ACA, Section 1557

NOTE:

- Variation, *e.g.* state mandated benefits
- Limited long term services & supports

Importance of Medicaid

- Low-income children (e.g., <math><133\%</math> FPL; children with disabilities)
- Early & Periodic, Screening, Diagnostic & Treatment (EPSDT)
 - Children & youth <math><21</math> years



EPSDT Screening Requirements:

- Medical, including 2X3 lead blood assessment
- Vision, including eyeglasses
- Hearing, including hearing aids
- Dental, including relief of pain, restoration of teeth, maintenance of dental health

EPSDT Treatment Requirements:

- All services that can be covered under state Medicaid plan (mandatory and optional), *e.g.*
 - ✓ Case management
 - ✓ In-home skilled nursing
 - ✓ Home health aides
 - ✓ Personal care services
 - ✓ Medical equipment and supplies
 - ✓ Physical, occupational, and speech therapy
 - ✓ Respiratory therapy
 - ✓ Rehabilitative services
 - ✓ Transportation and related services

EPSDT Treatment Requirements:

- Services necessary to **correct or ameliorate** physical and mental illnesses and conditions
- **Arrange for** corrective treatment the child need, directly or through referral

EPSDT Interplay with ADA/504 Disability Rights

- Integration mandate to ensure qualified individuals with disability is living in least restrictive setting
- Standards, criteria, or methods of administration that have the effect of discriminating on the basis of disability; or that perpetuate discrimination
- Remedy: Reasonable Accommodations



Enforcing Children's Rights, e.g.

- ***O.B. v. Norwood*** (IL): (1) arrange in-home nursing for children with medically complex conditions (2) with reasonable promptness, (3) ensure least restrictive setting
- ***Rosie D. v. Romney*** (MA): support services for children with serious emotional disturbances, including crisis intervention, in-home behavioral supports
- ***Radaszewski v. Maram*** (IL): in-home services for individual reaching 21 years
- ***Salazar v. D.C.*** (DC): clinical guidelines for Medicaid in-home services



THANK YOU

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Key Thoughts

- How do the legal rights discussed in the manuscript of Perkins and Agrawal relate to the basic child right to health?
- How can the principles, standards and norms of child rights, social justice and health equity be used to expand the context and approach to advancing the rights of children with medical complexities?
- What is a Child Rights-based Approach (CRBA) to health and well-being and how can it be used to structure and advance the care of children with medical complexities?

Edwin Simpser, MD

President and CEO, St. Mary's Healthcare System for Children



Key Thoughts

- Why don't Children with Medical Complexity receive the care that is mandated? What causes the gaps between their rights and mandates and the actual services received?
- My kingdom for a nurse!
- What parent of a medically complex child has the time and energy to file a lawsuit? Where is the oversight?
- How do we overcome the lack of evidence and the lack of value-based models in determining service delivery for this population?

Submit your questions in the question box



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