

THE FREEDOM
TRAIL
TO RESPITE



15th National Lifespan Respite Conference

October 15 to 17, 2013 ~ Boston



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The Journey to Accountability Must Embrace The Path of Respite

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Learning Objectives

- Discuss implications for leveraging the patient- and family-centered care movement to advance advocacy for respite care;
- Propose a strategic approach for integrating respite care resources into delivery systems



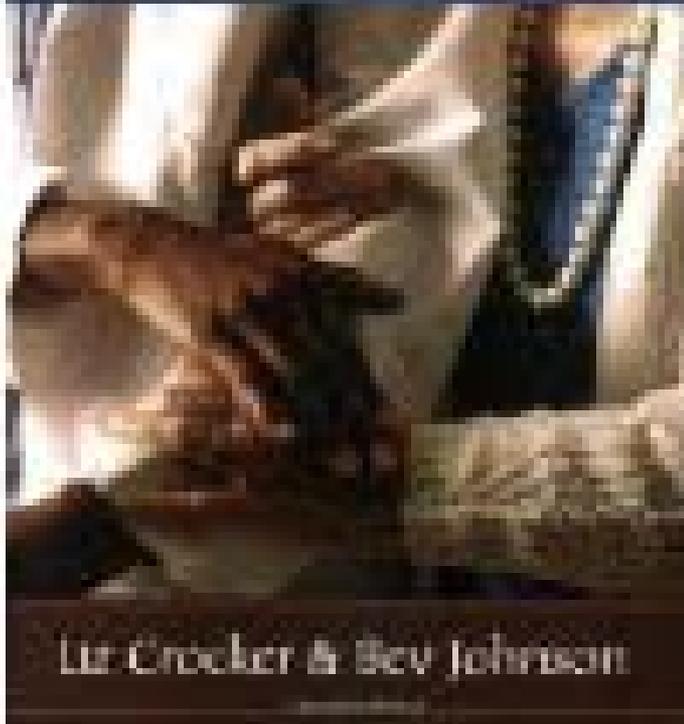
A True Vignette

- The Value of Asking Questions
- “You are pretty smart for a pediatrician.”
- Is there anything I can take that won’t make me lose my hair?
- I wish we knew about...
- How do they know what’s important to our family if they don’t ask us?
- The morphine comes from where?



Privileged Presence

Physical Touching in Pediatrics and Health Care



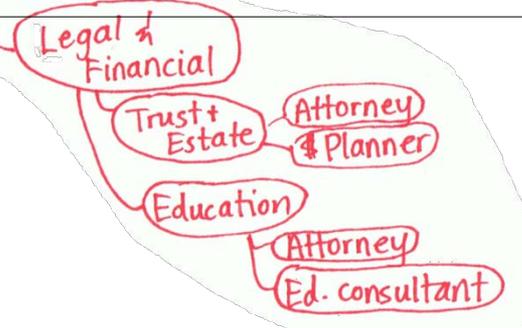
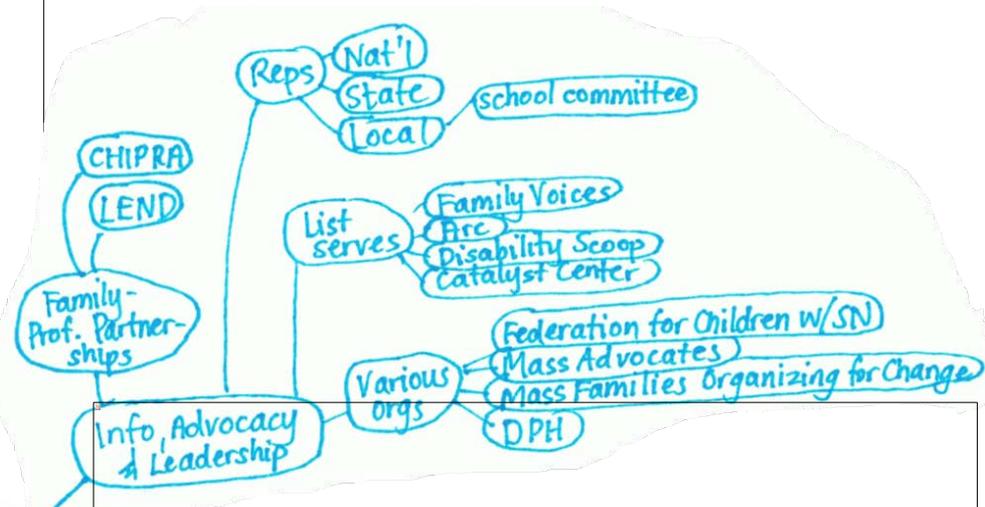
Liz Crocker & Bev Johnson



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Impact on Family Child with Autism

%CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child

ASD	31.0
non-ASD	19.5

%CSHCN whose conditions cause financial problems for the family

ASD	38.6
non-ASD	16.7

%CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care

ASD	25.6
non-ASD	8.7

%CSHCN whose conditions cause family members to cut back or stop working

ASD	57.2
non-ASD	21.7

<http://www.cshcndata.org>



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Medical Homes will not be successful unless...

...there is integration of care across the continuum, from
patient/ family perspective



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Definition of Integrated Care

Integrated care is the seamless provision of health care services, from the perspective of the patient and family, across the entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries.

(Antonelli, Care Integration for Children with Special Health Needs: Improving Outcomes and Managing Costs. National Governors Association Center for Best Practices)



Strategic Approach to Care Integration

- Care Coordination is the set of activities which occurs in “the space between”
 - Visits, Providers, Hospital stays
- Care Coordination is Necessary but not Sufficient to Achieve Integration
- Only way to succeed is to engage all stakeholders– including patients and families– as participants and partners





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The Lifespan Respite Care Act of 2006

- 1. Expand and enhance respite care services to family caregivers;**
- 2. Improve statewide dissemination and coordination of respite care**
- 3. Improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.**



Wouldn't It Be Nice If...

- There was no disintegration
- Patients/ Families/ Caregivers were given information when they needed it, and in a fashion that made it actionable?



What is Respite?

Respite services, planned or emergency, provide caregivers a needed break from their ongoing responsibilities, enabling them to keep their family unit intact and healthy.

Respite services can be beneficial, meaningful, and enjoyable to both the caregiver and the care receiver. Lifespan respite acknowledges that families looking for respite services share a common need regardless of the age or diagnosis of the individual that requires care.



What Do We Need Collectively?

- Time for renewal and respite care can provide you with the time to do that.
- Information about diagnosis
- Ability to navigate health care “system”
- Mentorship?



Opportunities in Era of Health Care Reform



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Achieving the Triple Aim



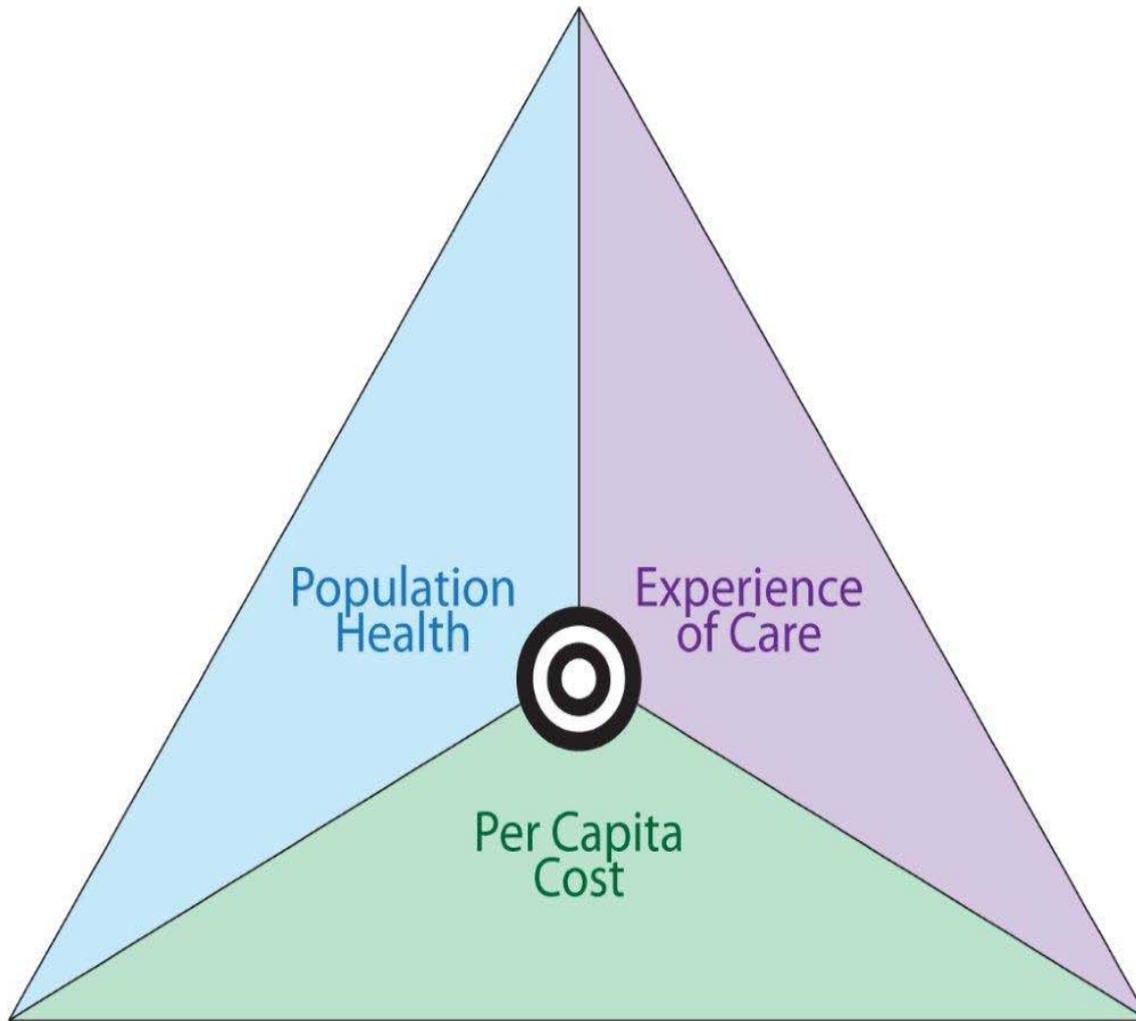
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Triple Aim

Triple Aim

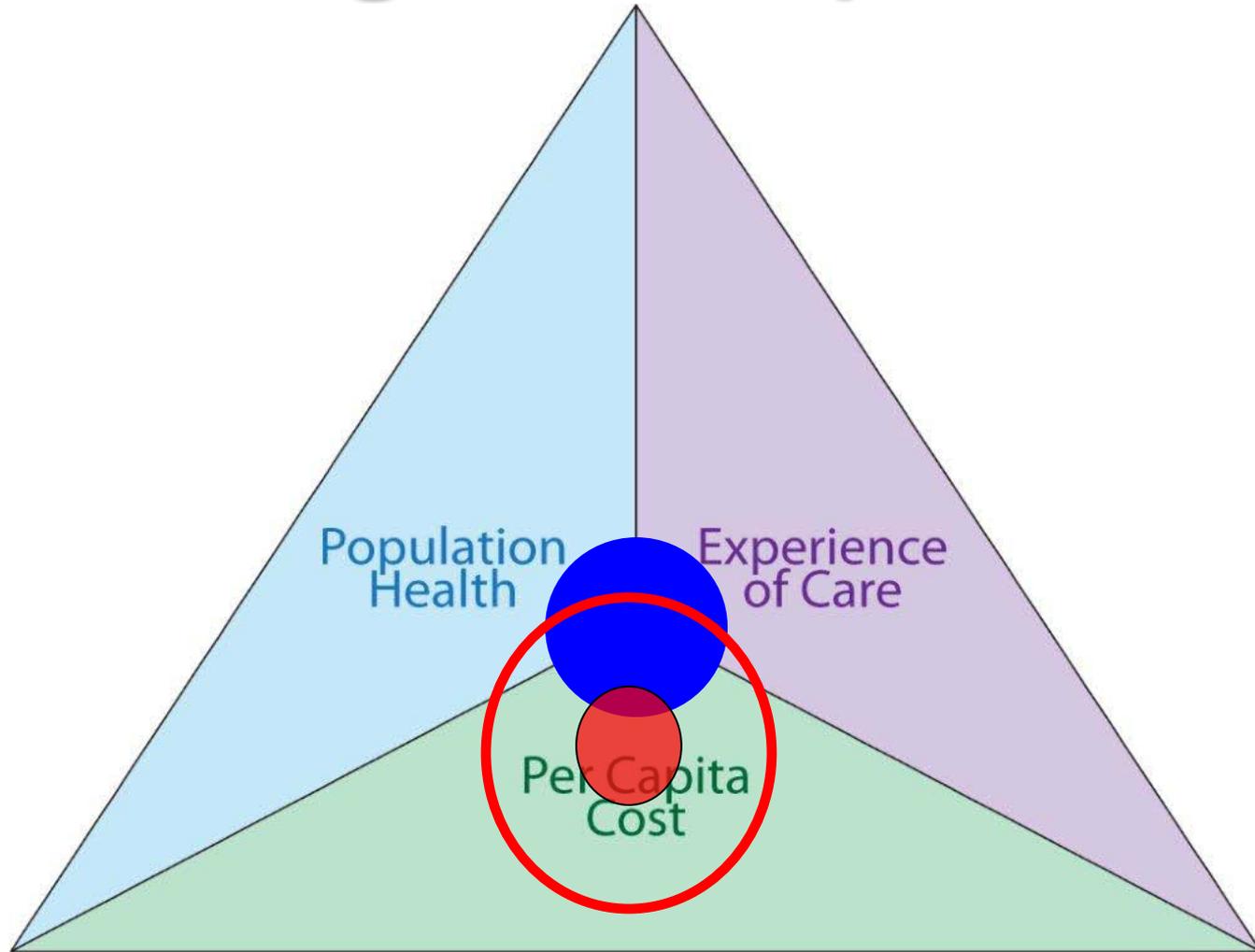


Principles reflect:

- Patient-centeredness and family engagement
- Quality care for patients of all ages, populations, service locations, and sources of coverage
- Elimination of disparities
- Alignment of public and private sectors



The Urgent “Triple Aim”



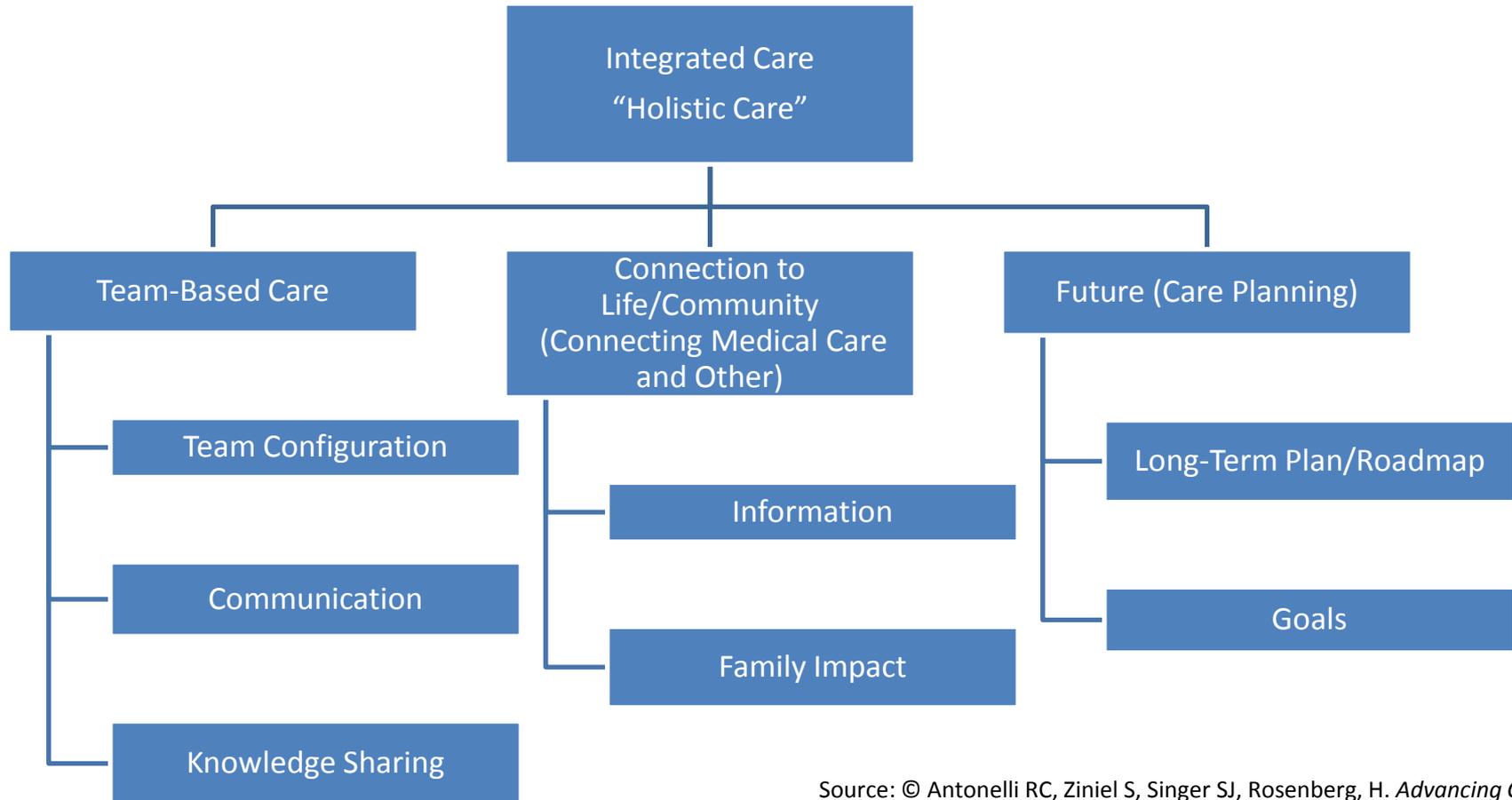


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Integrated Care Domains



Source: © Antonelli RC, Ziniel S, Singer SJ, Rosenberg, H. *Advancing Care Integration in Child Health*, Boston Children's Hospital. Funded by Lucile Packard Foundation for Children's Health. 10/2013.

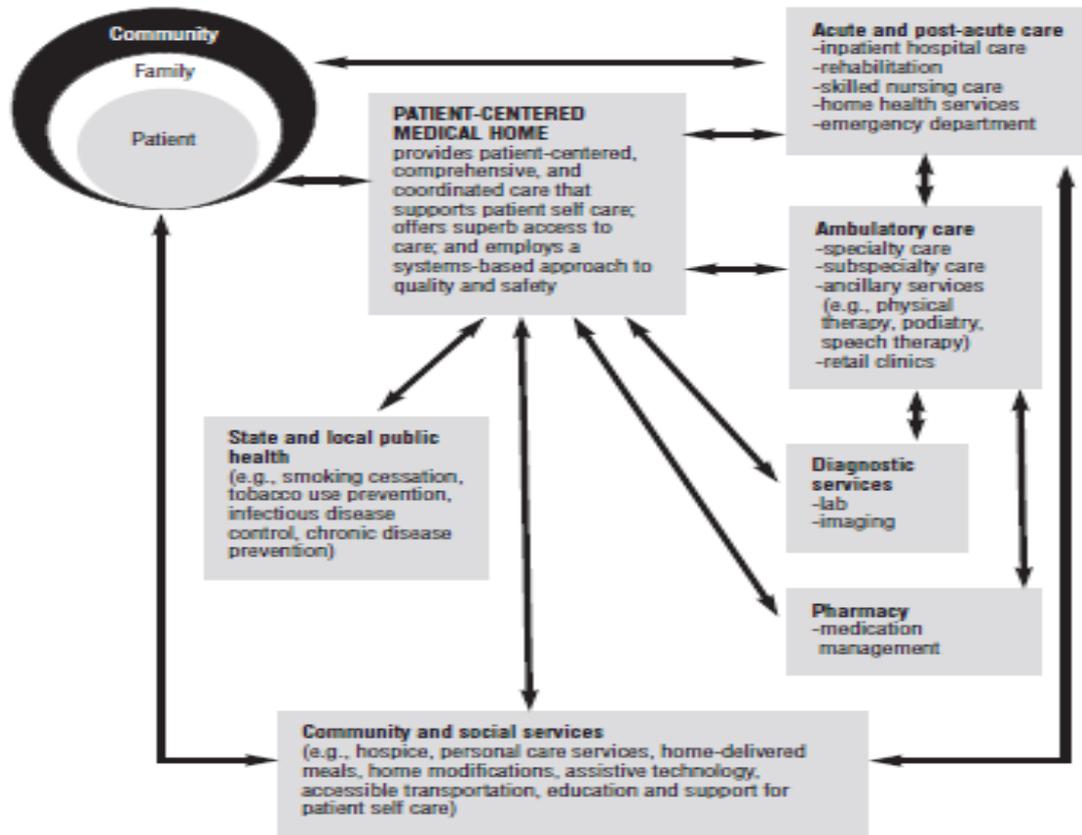


Capturing the Value of Respite

- Measures
 - Experience
 - Empowerment
 - Resource Utilization
 - Quality and Safety
 - Economic outcomes



Figure 1. Key actors and the flow of information in the medical neighborhood



Taylor, Lake, et al, Coordinating Care in the Medical Neighborhood, AHRQ, 2011.



MA Child Health Quality Coalition

Framework for Care Coordination Accountability for children with behavioral health needs

Care Coordination Activities

Family-driven, youth-guided

- Shared decision making, “doing with” families
- Patient needs and preferences are understood
- Skill building: family capacity building, care team skills

Facilitate transitions: making and tracking referrals

- Family engagement: family goals, NEED for referral
- Ingredients of a “warm” handoff
- Information needed at transition points

Creating, maintaining care plan

- Measures to monitor effective co-developed care plans
- Family engagement in setting goals, co-created plans
- Teach back
- Training

Linking to community resources

- Accountability framework
- Synergies/reducing duplication

Transition to adult care/transition out of programs

- Critical for youth with special health care needs







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