Making Connections: The Critical Role of Family-Centered Care in Addressing Social Determinants of Health for CYSHCN

A webinar series brought to you by the National Resource Center for Patient/Family-Centered Medical Home, Bright Futures National Center, and the STAR Center

Thursday, June 18, 2020
10 – 11am Central

Presented by Amy Houtrow, MD, MPH, PhD, FAAP
Moderated by Tom Scholz, MD, FAAP
MODERATOR

Thomas Scholz, MD, FAAP
Director, Iowa CYSHCN Program
Director, Division of Child and Community Health at the University of Iowa
ABOUT THE PARTNERS

• National Resource Center for Patient/Family-Centered Medical Home
• Bright Futures National Center
• Screening Technical Assistance & Resource (STAR) Center
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• Dr. Houtrow has funding from
  ▪ NIH NICHD
  ▪ CDC
  ▪ PCORI
  ▪ MCHB
  ▪ Pennsylvania Dept of Health

• We do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.
LEARNING OBJECTIVES

• Describe data trends related to the impacts of SDOH on CYSHCN.
• Increase understanding of the medical home model in addressing SDOH for CYSHCN at the state, community, and clinical levels.
• Identify strategies being implemented by state MCH Title V / CYSHCN programs, families, and primary care pediatricians to address SDOH for CYSHCN by using components of the medical home model.
S**ocial Determinants of Health Resources**

- Identification and Screening of Social Determinants of Health among Children with Special Health Care Needs in Medicaid Factsheet
- Integrating Social Determinants of Health Into Health Supervision Visits Implementation Tip Sheet
- Promoting Lifelong Health for Families and Communities
- *Bright Futures Tool & Resource Kit, 2nd Edition*
- Social Determinants of Health Information and Resources
  - Conversation Simulations for SDOH Counseling

*American Academy of Pediatrics*
FACULTY

Amy Houtrow, MD, MPH, PhD, FAAP
Chief, Division of Pediatric Rehabilitation Medicine
Vice Chair of Physical Medicine and Rehabilitation
Director, Spina Bifida Program
Professor of Physical Medicine and Rehabilitation, University of Pittsburgh School of Medicine
Program Director, Fellowship in Pediatric Rehabilitation Medicine
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We have a lot of work to do, People
GOALS

• Understand basic trends in social determinants of health

• Describe trends related to the impacts of social determinants of health on children and youth with special health care needs (CYSHCN)

• Review access to the medical home and family centered care for CYSHCN

• Increase understanding of the medical home model in addressing SDOH for CYSHCN
TERMS TO DEFINE

- Children and youth with special health care needs
- Health
- Social determinants of health
- Health equity
- Medical home and family-centered care
Children and youth with special health care needs (CYSHCN) “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”

A New Definition of Children With Special Health Care Needs

Merle McPherson, Polly Arango, Harriette Fox, Cassie Lauver, Margaret McManus, Paul W. Newacheck, James M. Perrin, Jack P. Shonkoff and Bonnie Strickland

Pediatrics July 1998, 102 (1) 137-139; DOI: https://doi.org/10.1542/peds.102.1.137

Source: https://www.childhealthdata.org/browse/survey/results?q=6919&r=1
Children's health should be defined as the extent to which an individual child or groups of children are able or enabled to: a) develop and realize their potential; b) satisfy their needs; and c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments.
FIGURE 1. A New Model of Children’s Health and Its Influences

Source: https://www.nap.edu/catalog/10886/childrens-health-the-nations-wealth-assessing-and-improving-child-health
SOCIAL DETERMINANTS OF HEALTH

- Conditions in which people are born into, live, learn, play, work and grow up
  - Individual level factors
  - Interpersonal level factors
    - Family
    - Friends
    - Teachers
  - Health systems factors
  - Geographic factors
  - Cultural factors
    - Stigma, racism, discrimination
**Health Equity**

“Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.”

Maslow's hierarchy of needs

Physiological needs
- air, water, food, shelter, sleep, clothing, reproduction

Safety needs
- personal security, employment, resources, health, property

Love and belonging
- friendship, intimacy, family, sense of connection

Esteem
- respect, self-esteem, status, recognition, strength, freedom

Self-actualization
- desire to become the most that one can be

MEDICAL HOME

A medical home is not a building or a place. It is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families.

- Personal doctor or nurse
- Usual source for sick care
- Family-centered care
- No problems with referrals, if needed
- Care coordination, if needed

Source: https://medicalhomes.aap.org/Pages/default.aspx
Family-Centered Care

Family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

Family-centered care is a respectful family/professional partnership that honors the strengths, cultures, traditions, and expertise that everyone brings to the relationship. Family-centered care is the standard of practice which results in high quality services.

A medical home provides family-centered care through a trusting, collaborative, working partnership with families, respecting their diversity, and recognizing that they are the constant in their child’s life.

Source: https://medicalhomes.aap.org/Pages/Providing-Family-Centered-Care.aspx
FAMILY-CENTERED CARE

- Provider spends enough time with your child
- Provider listens carefully to you
- Provider is sensitive to family values/customs
- Provider gives needed information
- Family feels like a partner in care
**SYSTEM OF CARE GOALS**

**MATERNAL AND CHILD HEALTH BUREAU**

**Community-based Services**
Ensure community services are organized for easy use by families.

**Early Continuous Screening**
Ensure children are screened early and continuously for special health care needs.

**Access to Medical Home**
The number of children with special health care needs who have a medical home that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

**Transition to Adulthood**
The percent of adolescents with special health care needs who have received the services necessary to transition to all aspects of adult life, including adult health care, work, and independence.

**Adequate Insurance**
The number of children who are adequately insured.

**Families as Partners**
Ensure families are partners in decision making.

DISCRIMINATION
The Impact of Racism on Child and Adolescent Health
Maria Trent, Danielle G. Dooley, Jacqueline Dougé, SECTION ON ADOLESCENT HEALTH
Pediatrics August 2019, 144 (2) e20191765; DOI: https://doi.org/10.1542/peds.2019-1765

Social Inequality and Racial Discrimination: Risk Factors for Health Disparities in Children of Color
Kathy Sanders-Phillips, Beverlyn Settles-Reaves, Doren Walker and Janeese Brownlow
Pediatrics November 2009, 124 (Supplement 3) S176-S186; DOI: https://doi.org/10.1542/peds.2009-1100E
RACIAL SOCIALIZATION AND HEALTH

**Exposure to racial discrimination**
- Exposure at the microsystem (individual) level:
  - Childhood experiences of racial discrimination (e.g., teasing, bullying, isolation)
  - Observation of parent, family member, and peer experiences of racial discrimination
  - Quality of parenting and racial socialization

- Exposure at the macrosystem (structural) level:
  - Media
  - Schools (e.g., teachers)
  - Social, political, and economic policies
  - Police and other adults

**Psychological and biological responses**
- Psychological distress:
  - Decreased self-efficacy
  - Depression
  - Hopelessness
  - Anxiety
  - Anger/aggression
  - Perceptions of injustice/lower levels of empathy

- Changes in allostatic load:
  - Decreased immune function
  - Increased cortisol levels
  - Increased blood pressure
  - Increased heart rate

**Child health outcomes and disparities**
- Health outcomes and disparities related to:
  - Increased likelihood of low birth weight or premature birth
  - Increased risk behaviors such as drug use and/or sexual risk-taking
  - Increased aggression/violent behaviors
  - Increased risk of chronic illness such as cardiovascular disease
  - Increased susceptibility to infectious diseases such as HIV/AIDS

POVERTY

• In 2018, 16% of children live below the federal poverty level ($26,200 in 2020 for a family of 4) = ~12 million children

• ~43% of children live in families in which their income cannot meet their basic needs

Sources:
https://aspe.hhs.gov/poverty-guidelines
http://www.nccp.org/topics/childpoverty.html
### Basic Needs Budget Calculator

**Basic Needs Budget: District of Columbia, DC (2017)**  
Single-parent family with 2 children, ages 3 and 6

<table>
<thead>
<tr>
<th>Item</th>
<th>Annual</th>
<th>Monthly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rent and utilities</td>
<td>$20,952</td>
<td>$1,746</td>
</tr>
<tr>
<td>Food</td>
<td>$6,843</td>
<td>$570</td>
</tr>
<tr>
<td>Child care (center-based)</td>
<td>$14,010</td>
<td>$1,168</td>
</tr>
<tr>
<td>Health insurance premiums (employer-based)</td>
<td>$6,054</td>
<td>$505</td>
</tr>
<tr>
<td>Out-of-pocket medical</td>
<td>$708</td>
<td>$59</td>
</tr>
<tr>
<td>Transportation</td>
<td>$2,096</td>
<td>$175</td>
</tr>
<tr>
<td>Other necessities</td>
<td>$8,936</td>
<td>$745</td>
</tr>
<tr>
<td>Debt</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Payroll taxes</td>
<td>$5,531</td>
<td>$461</td>
</tr>
<tr>
<td>Income taxes (includes credits)</td>
<td>$7,167</td>
<td>$597</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>$72,297</strong></td>
<td><strong>$6,025</strong></td>
</tr>
</tbody>
</table>

**Hourly wage needed:** $35  
**Percent of the federal poverty level:** 354%

CHILDHOOD POVERTY TRENDS BY RACE

EXTREME POVERTY TRENDS BY RACE

Children In Extreme Poverty (50 Percent Poverty) By Race And Ethnicity (Percent)


National KIDS COUNT
KIDS COUNT Data Center, datacenter.kidscount.org
A project of the Annie E. Casey Foundation
27% of children live in homes where parent(s) lack secure employment.

Children Whose Parents Lack Secure Employment (Percent) - 2009-2018

National KIDS COUNT
KIDS COUNT Data Center, datacenter.kidscount.org
A project of the Annie E. Casey Foundation

17% of children are food insecure

Children Living In Households That Were Food Insecure At Some Point During The Year (Percent)

31% of children

Renters in poverty spend 63% of income on rent (Collinson et al 2015)

Children Living In Households With A High Housing Cost Burden (Percent) - 2009-2018

HOMELESSNESS

- Homelessness negatively impacts education, physical and mental health
- 1/5 of people who experience homelessness are children
  - Moving from home to home
  - High eviction rates
  - Living in cars
- ½ of homeless children are black

Source: https://www.childrensdefense.org/policy/resources/soac-2020-housing/
QUALITY EDUCATION
8th Graders Below Grade Level for Math by Race

Eighth Graders Who Scored Below Proficient Math Achievement Level By Race (Percent) - 2019

Source: https://datacenter.kidscount.org/data/bar/7665-eighth-graders-who-scored-below-proficient-math-achievement-level-by-race?loc=1&loct=1#1/any/false/1729/107,9,12,10/14819

National KIDS COUNT
KIDS COUNT Data Center, datacenter.kidscount.org
A project of the Annie E. Casey Foundation
More than twice as many black children are expelled compared to white children.

Children Who Have Been Expelled From School By Race (Rate Per 10,000) - 2013-2014

Source: https://datacenter.kidscount.org/data/bar/8834-children-who-have-been-expelled-from-school-by-race?loc=1&loct=1#1/any/false/1246/10,9,12,1,13/17707
YOUTH IN JUVENILE DETENTION BY RACE

4.6 times as many black youth are in detention as white youth

Youth Residing In Juvenile Detention, Correctional And/Or Residential Facilities By Race And Hispanic Origin (Rate Per 100,000) - 2017

• Discipline problems thought as criminal problems
• Fewer nurses
• Fewer counselors
• More resource officers
SAFE ENVIRONMENTS
SAFE NEIGHBORHOOD BY INCOME

Source: https://www.childhealthdata.org/browse/survey/results?q=7245&r=1
SAFE NEIGHBORHOOD BY RACE

Source: https://www.childhealthdata.org/browse/survey/results?q=7245&r=1&g=720
CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN) AND SOCIAL DETERMINANTS OF HEALTH

- Poverty
- Race
- Health
CYSHCN are more likely to be poor

Nearly half of CYSHCN are poor or near poor

40% of other children are poor or near poor

- 400%+ FPL
- 200-339% FPL
- 100-199% FPL
- 0-99% FPL
Understanding Factors Associated With Work Loss for Families Caring for CSHCN
Megumi J. Okumura, Jeanne Van Cleave, Sangeeth Gnanasekaran and Amy Houtrow
*Pediatrics* 2009;124;S392

Child somewhat limited
Child limited a great deal
Unstable health care needs
Single parent
Living in or near poverty

<table>
<thead>
<tr>
<th>Condition</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child somewhat limited</td>
<td>0.9</td>
</tr>
<tr>
<td>Child limited a great deal</td>
<td>2.6</td>
</tr>
<tr>
<td>Unstable health care needs</td>
<td>3.9</td>
</tr>
<tr>
<td>Single parent</td>
<td>7.9</td>
</tr>
<tr>
<td>Living in or near poverty</td>
<td>10</td>
</tr>
</tbody>
</table>
POOR HEALTH BY INCOME

Source: https://www.childhealthdata.org/browse/survey/results?q=6844&r=1&g=728
DISABILITY BY INCOME

Source: https://www.childhealthdata.org/browse/survey/results?q=6930&r=1&g=728
CYSHCN are more likely to be Black

Source: https://www.childhealthdata.org/browse/survey/results?q=6919&r=1&g=720
POOR HEALTH BY RACE

Source: https://www.childhealthdata.org/browse/survey/results?q=6844&r=1&g=720
DISABILITY BY RACE

Hispanic: 10.0%
Black: 14.0%
White: 9.0%
Other: 10.0%

https://www.childhealthdata.org/browse/survey/results?q=6930&r=1&g=720
IN ORDER TO BENEFIT FROM HIGH QUALITY HEALTH CARE,
YOU NEED TO BE ABLE ACCESS IT
Receipt of Family-Centered Care

- 0-99% FPL: 70.0%
- 100-199% FPL: 80.0%
- 200-399% FPL: 85.0%
- 400%+ FPL: 95.0%
- Total: 90.0%

[Source: https://www.childhealthdata.org/browse/survey/results?q=7101&r=1]
Receipt of Family Centered Care

- White
- Black
- Hispanic
- Asian
- Other
CARE IN A MEDICAL HOME CYSHCN

57% have care in a medical home

43% have care in a medical home

Source: https://www.childhealthdata.org/browse/survey/results?q=7274&r=1
CYSHCN CARE IN MEDICAL HOME BY INCOME

Source: https://www.childhealthdata.org/browse/survey/results?q=7274&r=1&g=728
HEALTH STATUS AND THE MEDICAL HOME

Source: https://www.childhealthdata.org/browse/survey/results?q=6844&r=1&g=738
IN HEALTH CARE IT FEELS LIKE WE ARE ALWAYS TRYING TO SWIM UPSTREAM
THE BIG PICTURE

- Eliminate poverty
- Eliminate discrimination
Reducing Child Poverty by 50% in 10 Years

• It can be done!

Source: https://www.nap.edu/catalog/25246/a-roadmap-to-reducing-child-poverty
Reducing Child Poverty by 50% in 10 Years

- Convert the Child and Dependent Care Tax Credit to a fully refundable credit that concentrates benefits to the families with the lowest incomes
- Increase the Supplemental Nutrition Assistance Program
- Increase housing voucher toward families with children
- Expand the Earned Income Tax Credit to increase payments

Source: https://www.nap.edu/catalog/25246/a-roadmap-to-reducing-child-poverty
Costs ~$90.7 billion/year

Payoff of ~$92.9 billion/year
ELIMINATING DISCRIMINATION

THE INTERNATIONAL CONVENTION ON THE ELIMINATION OF ALL FORMS OF RACIAL DISCRIMINATION *

By

EGON SCHWELB †

On December 21, 1965, the General Assembly of the United Nations unanimously ¹ adopted and opened for signature and ratification the International Convention on the Elimination of All Forms of Racial Discrimination. ² Commenting on the event and on the work of the twentieth (1965) session of the General Assembly, the representative of Ghana said: This was its finest hour. ³ Earlier,
Policies to Support Community Solutions

- Taxation reforms
- Housing and urban planning
- Education (especially early education)
- Civil rights law and policy
- Criminal justice reform
- Health Policy
  - Focus on prevention and early engagement

Source: https://www.nap.edu/catalog/24624/communities-in-action-pathways-to-health-equity
Health Development: Reducing Risk and Optimizing Promoting and Protective Factors

Ready to learn

- Poverty
- Lack of health services
- Toxic Stress
- Parent education
- Emotional Health Literacy
- Appropriate Discipline
- Reading to child
- Health Services
- Pre-school

“Healthy” Trajectory
“At Risk” Trajectory
“Delayed/Disordered” Trajectory

Age

6 mo 12 mo 18 mo 24 mo 3 yrs 5 yrs
Early Infancy Early Toddler Late Toddler Late Preschool
Strengthen economic supports to families
- Strengthening household financial security
- Family-friendly work policies

Change social norms to support parents and positive parenting
- Public engagement and enhancement campaigns
- Legislative approaches to reduce corporal punishment

Provide quality care and education early in life
- Preschool enrichment with family engagement
- Improved quality of child care through licensing and accreditation

Enhance parenting skills to promote healthy child development
- Early childhood home visitation
- Parenting skill and family relationship approaches

Intervene to lessen harms and prevent future risk
- Enhanced primary care
- Behavioral parent training programs
- Treatment to lessen harms of abuse and neglect exposure
- Treatment to prevent problem behavior and later involvement in violence
Implement initiatives across systems to support children, families, other caregivers, and communities. Ensure trauma-informed systems, build a diverse and supported workforce, and align strategies that work across sectors.

Integrate and coordinate resources across the education, social services, and health care systems, and make them available to translate science to action.
ADVICE FOR THE PEDIATRIC HEALTH CARE PROVIDER

• Be aware of your own role in perpetuating inequities
• Make health equity a shared vision and value of your practice
• Develop explicit strategies for engagement of your community
• Make screening and addressing SDOH part of your practice
• Have community resources available
<table>
<thead>
<tr>
<th>Strengths and Protective Factors</th>
<th>Risk Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parents</strong></td>
<td></td>
</tr>
<tr>
<td>• Ability to access concrete support in times of need</td>
<td>• Parental dysfunction, separation, or divorce</td>
</tr>
<tr>
<td>• Social connections</td>
<td>• Few social or community connections</td>
</tr>
<tr>
<td>• Knowledge of parenting and child development</td>
<td>• Limited knowledge of parenting</td>
</tr>
<tr>
<td>• Personal resilience</td>
<td>• Difficulty with nurturing or fostering attachment</td>
</tr>
<tr>
<td>• Ability to enhance social and emotional competence of children</td>
<td></td>
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<tr>
<td>• Ability to foster nurturing and attachment</td>
<td></td>
</tr>
<tr>
<td><strong>Families</strong></td>
<td></td>
</tr>
<tr>
<td>• Nurturing adults who sensitively and consistently respond to their children’s needs</td>
<td>• Few adults who can provide a nurturing and responsive environment</td>
</tr>
<tr>
<td>• Stable, predictable, and consistent physical, social, and emotional family environments</td>
<td>• Family tobacco, alcohol, or drug use</td>
</tr>
<tr>
<td>• Freedom from fear and protection from physical or psychological harm</td>
<td>• Abuse or neglect</td>
</tr>
<tr>
<td>• Unstable physical, social, and emotional family environments</td>
<td></td>
</tr>
<tr>
<td><strong>Communities</strong></td>
<td></td>
</tr>
<tr>
<td>• Safe neighborhoods</td>
<td>• Poverty</td>
</tr>
<tr>
<td>• Safe and high-quality schools</td>
<td>• Food insecurity</td>
</tr>
<tr>
<td>• Stable and safe housing</td>
<td>• Housing insecurity</td>
</tr>
<tr>
<td>• Access to nutritious food</td>
<td>• Unsafe neighborhoods</td>
</tr>
<tr>
<td>• Access to job opportunities and transportation</td>
<td>• Unsafe and low-quality schools</td>
</tr>
<tr>
<td>• Access to medical care, including behavioral health and wellness care</td>
<td>• Limited employment and transportation opportunities</td>
</tr>
<tr>
<td>• Lack of access to medical care and social services</td>
<td></td>
</tr>
</tbody>
</table>
“Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”

–Dr Martin Luther King, Jr
RESOURCES

- NRC-PFCMH SDOH Resources
- Bright Futures SDOH Resources
- STAR Center SDOH Resources
- Association of Maternal and Child Health Programs SDOH Learning Network Fact Sheet
- National Survey of Children’s Health
- Centers for Disease Control and Prevention SDOH Resources
- Healthy People 2020 SDOH Resources
CONTACT INFORMATION

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- NRC-PFCMH
  - medical_home@aap.org
- Bright Futures National Center
  - brightfutures@aap.org
- STAR Center
  - screening@aap.org
PARTICIPANT QUESTIONS
JOIN US FOR EPISODE 2

• The webinar will feature 2 state Title V MCH / CYSHCN programs who will discuss how their states are addressing SDOH for CYSHCN

Tuesday, June 23, 2020
10 – 11am Central
Register on the NRC website,
www.medicalhomeinfo.aap.org
THANK YOU FOR YOUR PARTICIPATION!