Families as Partners Shaping Systems Change *to Accelerate Improvements in Child Health*

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Health Resources and Services Administration (HRSA)

HRSA Maternal & Child Health

Objectives

- **Provide a brief history of HRSA's Maternal and Child Health Bureau (MCHB) and family engagement**

- **Discuss opportunities for partnering with families to accelerate improvements in child health**

Brief History of MCHB and Family Engagement



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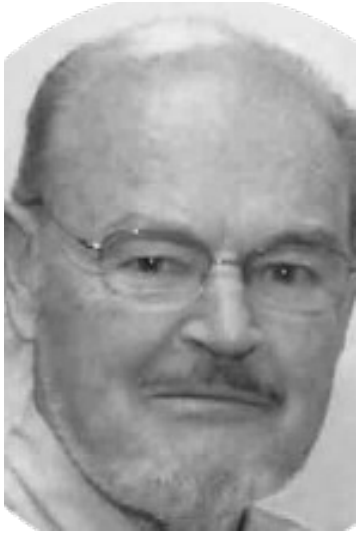
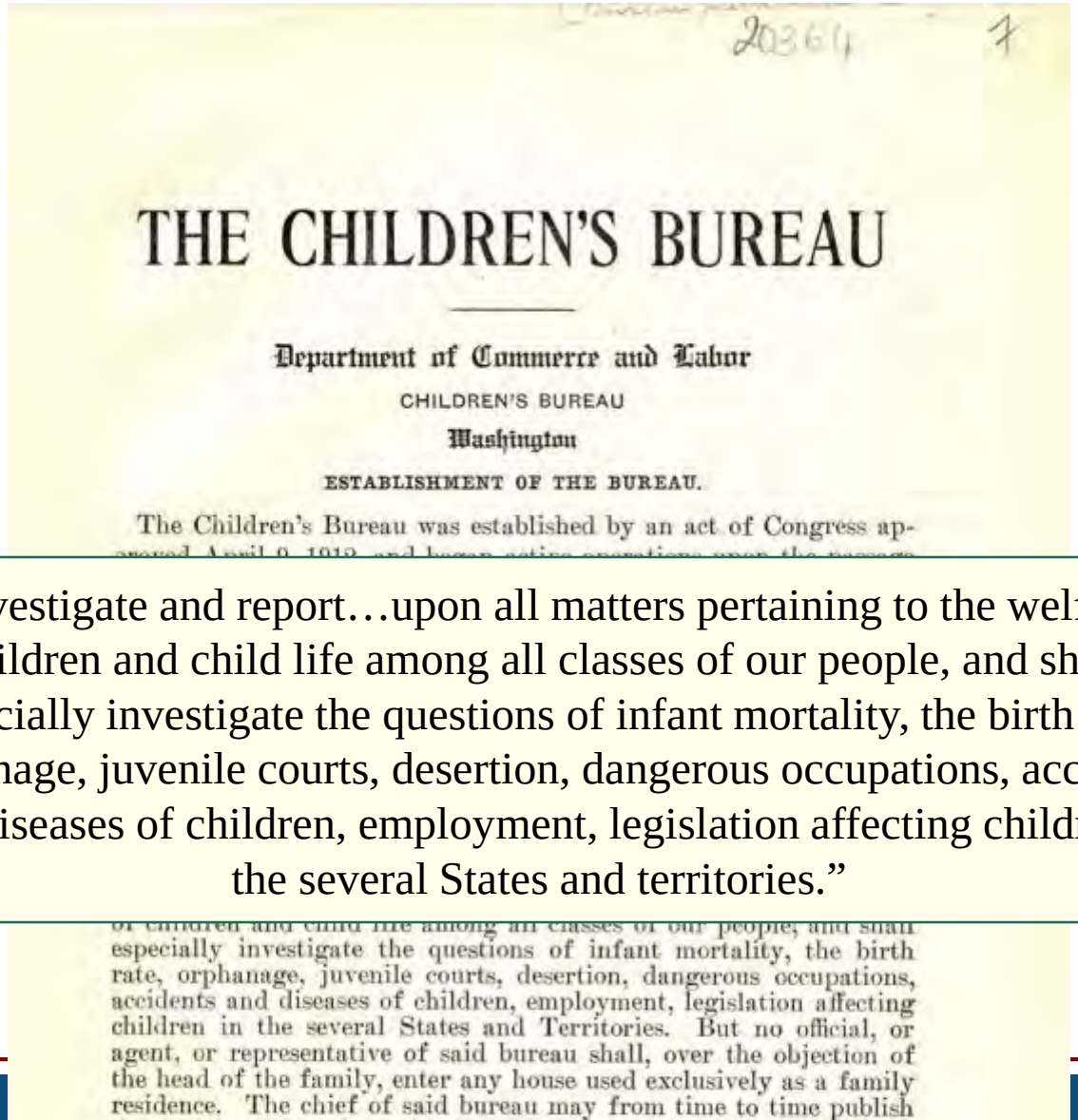



1912: Founding of the Children's Bureau



THE CHILDREN'S BUREAU

Department of Commerce and Labor

CHILDREN'S BUREAU

Washington

ESTABLISHMENT OF THE BUREAU.

The Children's Bureau was established by an act of Congress ap-

especially investigate the questions of infant mortality, the birth rate, orphanage, juvenile courts, desertion, dangerous occupations, accidents and diseases of children, employment, legislation affecting children in the several States and Territories. But no official, or agent, or representative of said bureau shall, over the objection of the head of the family, enter any house used exclusively as a family residence. The chief of said bureau may from time to time publish

"…investigate and report…upon all matters pertaining to the welfare of children and child life among all classes of our people, and shall especially investigate the questions of infant mortality, the birth rate, orphanage, juvenile courts, desertion, dangerous occupations, accidents and diseases of children, employment, legislation affecting children in the several States and territories."

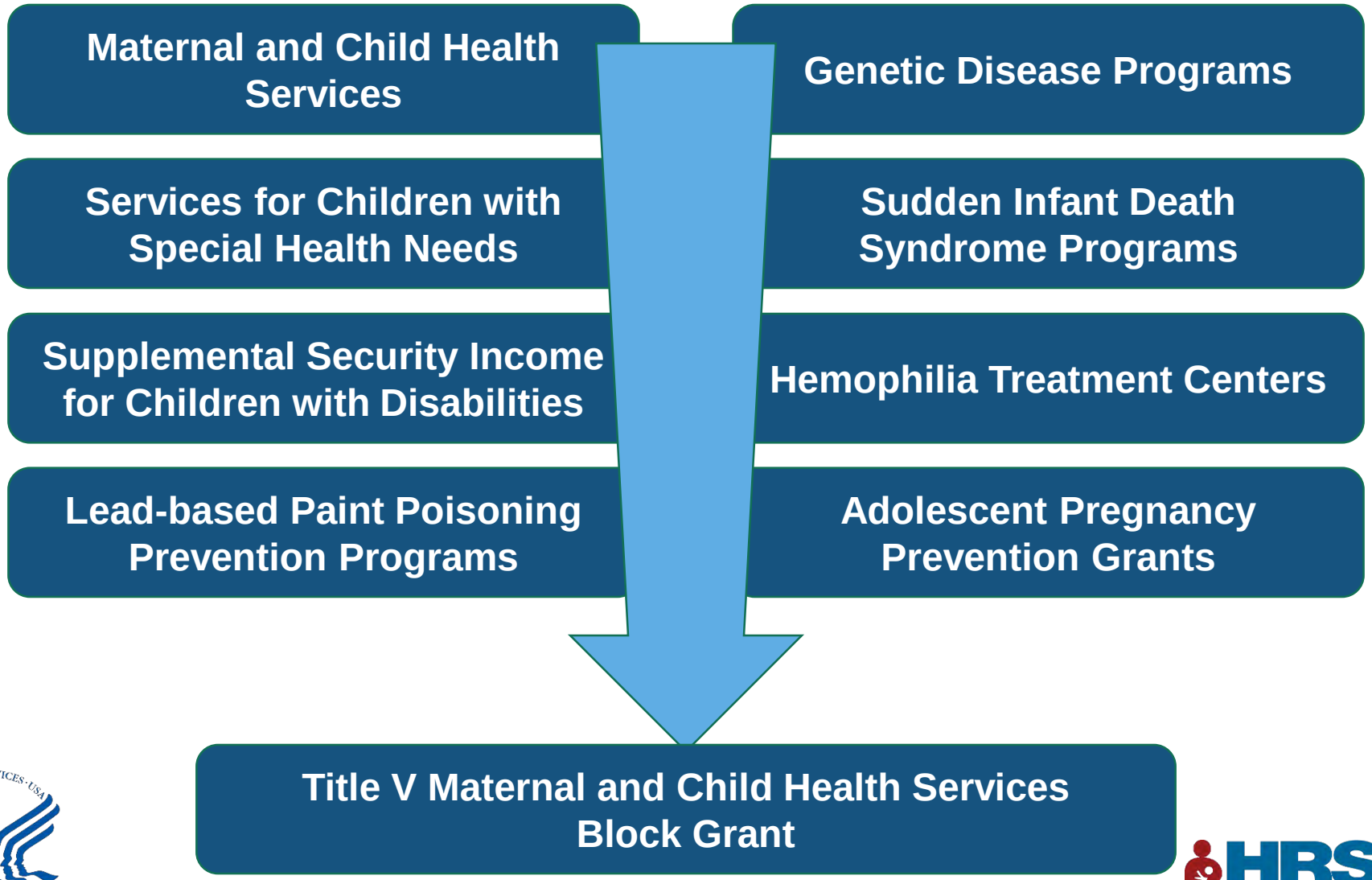
1935: Title V of the Social Security Act

Grants to states for Maternal and Child Welfare

- Maternal and child health services
- Crippled children's services
- Child welfare services
- Vocational rehabilitation
- Administration

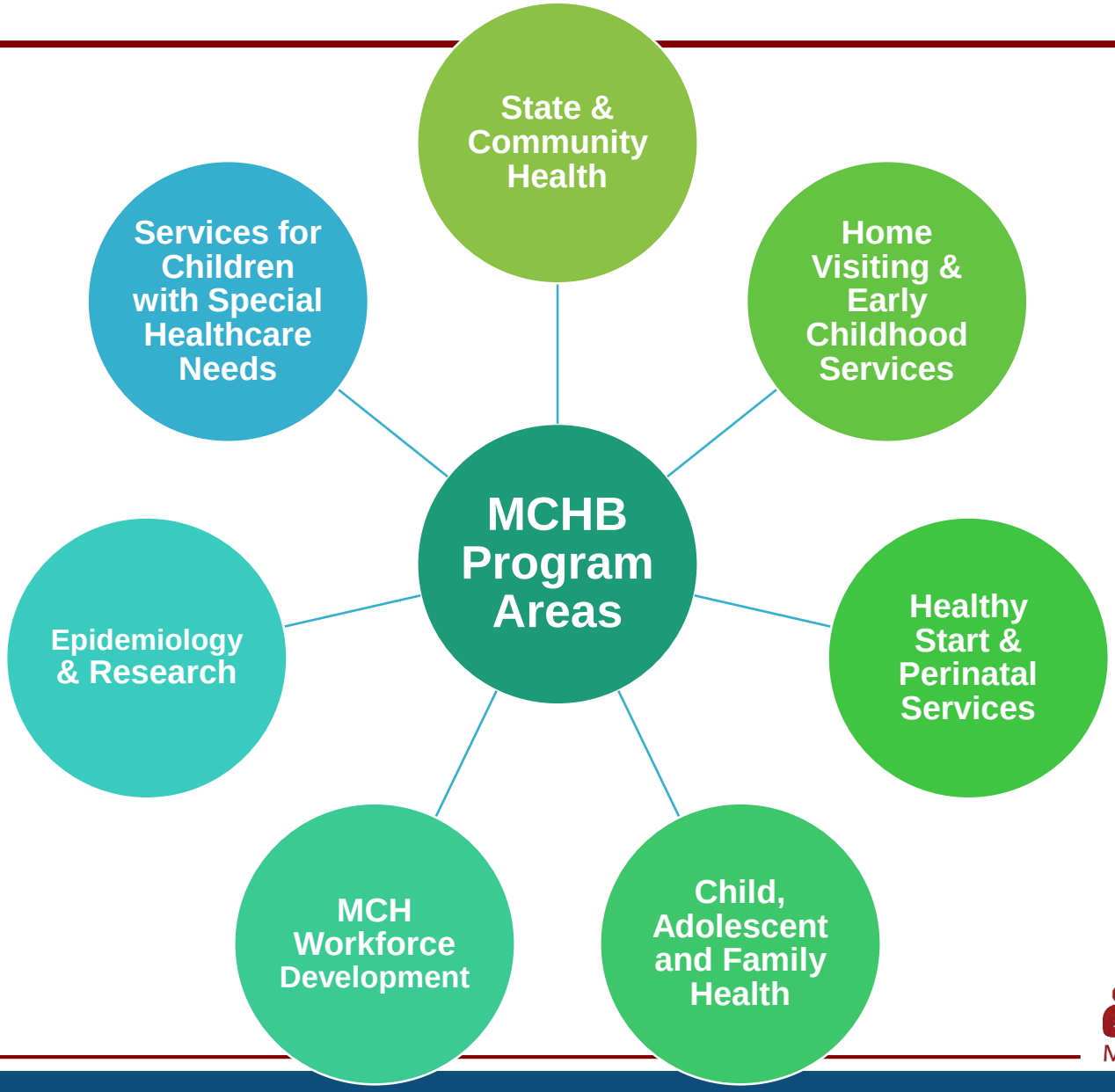
HRSA Maternal & Child Health

1981: Creation of the MCH Block Grant



HRSA Maternal & Child Health

Today's Maternal and Child Health Bureau



HRSA Maternal & Child Health

Maternal and Child Health Bureau

Mission:
Improve the health of America's mothers, children, and families.

HRSA Maternal & Child Health

Department of Health and Human Services (Operating Divisions)

Department of Health and Human Services (DHHS)

Administration for Children and Families (ACF)	Food and Drug Administration (FDA)
Administration for Community Living (ACL)	Health Resources and Services Administration (HRSA)
Agency for Healthcare Research and Quality (AHRQ)	Indian Health Service (IHS)
Agency for Toxic Substances and Disease Registry (ASTDR)	National Institutes of Health (NIH)
Centers for Disease Control and Prevention (CDC)	Substance Abuse and Mental Health Services Administration (SAMHSA)
Centers for Medicare and Medicaid Services (CMS)	

HRSA Maternal & Child Health

HRSA Bureaus

Health Resources and Services Administration (HRSA)

- Bureau of Health Workforce
- Bureau of Primary Health Care
- Healthcare Systems Bureau
- HIV/AIDS Bureau
- **Maternal and Child Health Bureau**

HRSA Maternal & Child Health

Maternal and Child Health Bureau
FY 2019 Total Budget: $1.33 billion

Maternal and Child Health Bureau Programs	FY2019 Enacted
Maternal and Child Health Block Grant	$677.7
Maternal, Infant and Early Childhood Home Visiting	$400.0
Healthy Start	$122.5
Autism and Other Developmental Disabilities	$50.6
Emergency Medical Services for Children	$22.3
Universal Newborn Hearing Screening	$17.8
Heritable Disorders	$16.4
Pediatric Mental Health Care Access	$10.0
Family-to-Family Health Information Centers	$6.0
Screening and Treatment for Maternal Depression	$5.0
Sickle Cell service Demonstration Program	$4.5

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Family Engagement in MCHB

- "Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system– direct care, organizational design and governance, and policy making—to improve health and health care. This partnership is accomplished through the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course."

Family Engagement in MCHB

1980s

- Development of medical home approach
- Surgeon's General Conferences
- First MCHB funding opportunity for family organizations
- First parent employed (as a parent) in state Title V program
- Block grant legislation changed to emphasize "family-centered, community-based, coordinated care"

Family Engagement in MCHB

1990s

- Family Voices receives funding from MCHB
- First conference for family leaders employed in Title V programs
- F2F HICs piloted in six states

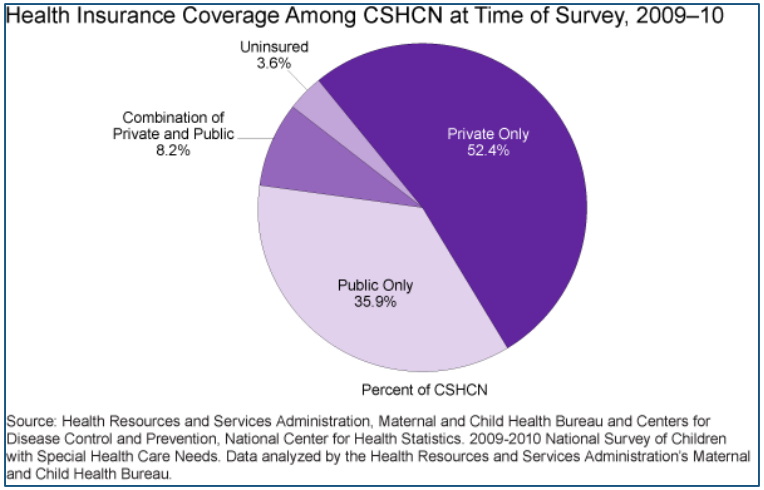
FAMILY VOICES®

HRSA Maternal & Child Health

Family Engagement in MCHB

2000-Present

- First National Survey of CSHCN
- AMCHP includes parent/family member on Board of Directors
- F2Fs funded in all states
- First family member elected as President of AMCHP Board



AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

HRSA Maternal & Child Health

Family Engagement in MCHB: Family-to-Family Health Information Centers

- **F2Fs in:**
  - 50 states
  - DC
  - Five territories
  - Three organizations serving tribal communities
- **In FY18:**
  - Outreach and information to **almost 1 million families** and **more than 374,000 professionals**
  - Individualized assistance and/or training to **181,938 families** and **83,859 professionals**

Family Engagement in MCHB: MCH Block Grant

- **30% of Title V funds** must be used to support services for CSHCN

- Application/annual report must include information on "**family-centered, community-based, coordinated care** (including care coordination services) for children with special health care needs (CSHCN) and to facilitate the development of community-based systems of services for such children and their families"

- Block grant applications must also report on **family partnerships**

Family Engagement in MCHB: Family Engagement & Leader Development

- Family leadership development:
  - Family leadership in Language and Learning Program (FL3)
  - National Genetics Education and Family Support Center
  - Newborn Screening Family Education Program
  - Leadership Excellence in Neurodevelopmental Disabilities (LEND) and Adolescent Health (LEAH)
- Other program activities:
  - Newborn Hearing Screening
  - Sickle Cell
  - Hemophilia
  - Autism
  - Epilepsy

A Paradigm for Improving Maternal and Child Health

Some Persistent Challenges

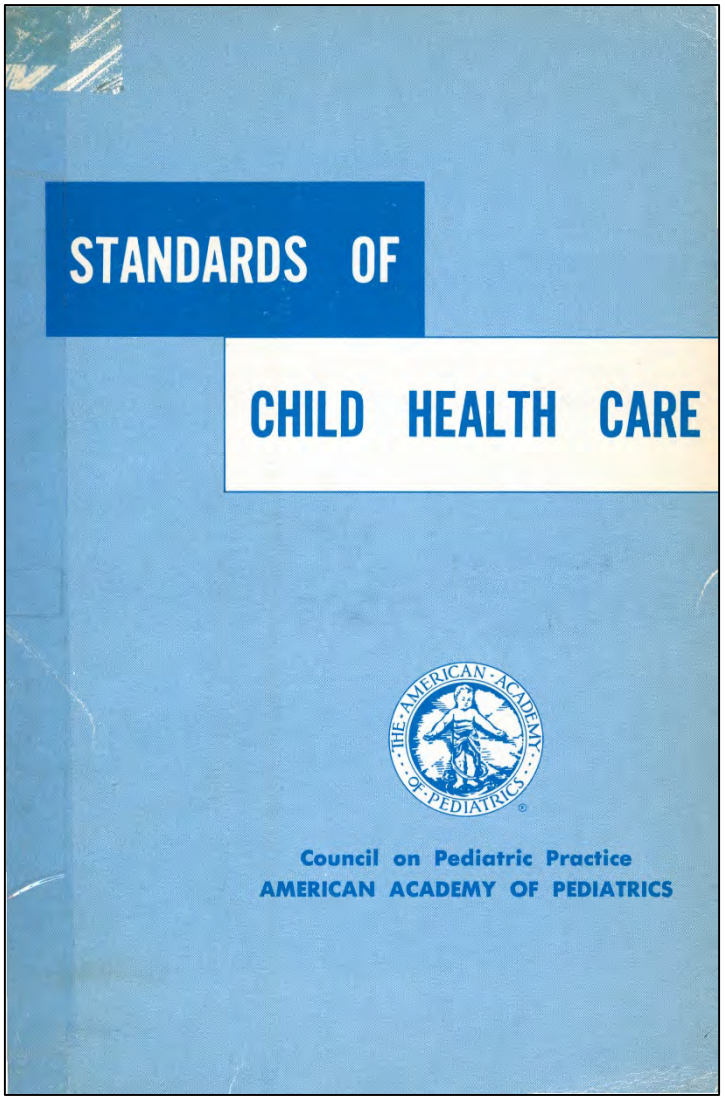
- Adolescent mental health
- Unsafe infant sleep positions
- Maternal mortality
- Medical home and transition for children and youth with special health needs
- Infant mortality

Accelerate.

Upstream.

Together.

Accelerate.



Medical home defined as “one central source of a child’s pediatric records”

“For children with chronic diseases or disabling conditions, the lack of a complete record and a ‘medical home’ is a major deterrent to adequate health supervision. Wherever the child is cared for, the question should be asked, ‘Where is the child’s medical home?’ and any pertinent information should be transmitted to that place”

Sia C, Tonniges TF, Osterhus E, Taba S. History of the Medical Home Concept. Pediatrics. May 2004, VOLUME 113 / ISSUE Supplement 4.
Image courtesy of American Academy of Pediatrics Library & Archival Services.

AMERICAN ACADEMY OF PEDIATRICS

The Medical Home

Ad Hoc Task Force on Definition of the Medical Home

The American Academy of Pediatrics believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a relationship of mutual responsibility an

ta base
n about
the child, including information about hospitalizations. This record should be accessible, but confidentiality must be assured.

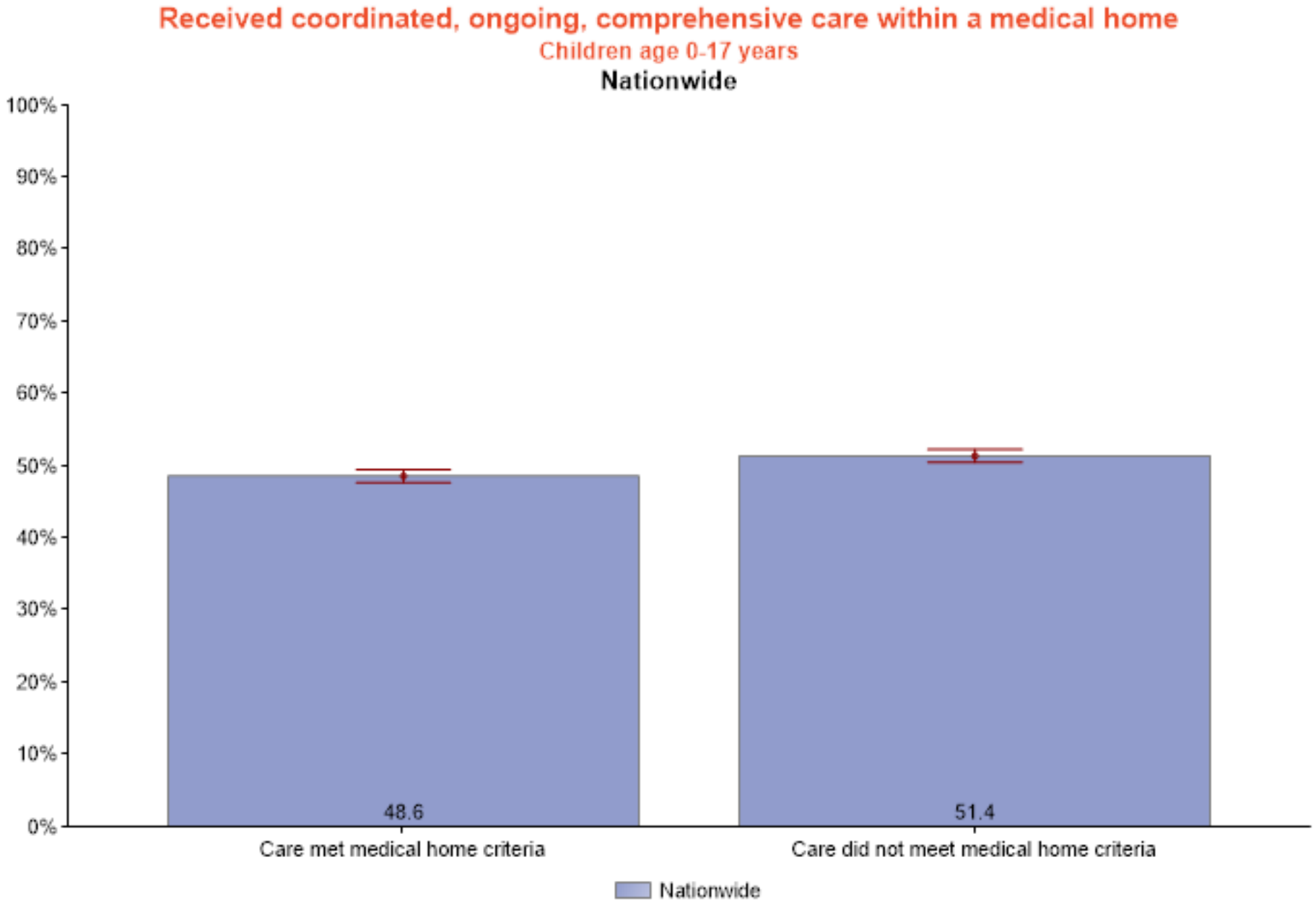
the "me
traditionally been provided by pediatricians in an office setting. In contrast, care provided through emergency departments, walk-in clinics, and other urgent-care facilities is often less effective and more costly.

We should strive to attain a "medical home" for all of our children. Although geographic barriers, personnel constraints, practice patterns, and economic and social forces make the ideal "medical home" unobtainable for many children, we believe that comprehensive health care of infants, children, and adolescents, wherever delivered, should encompass the

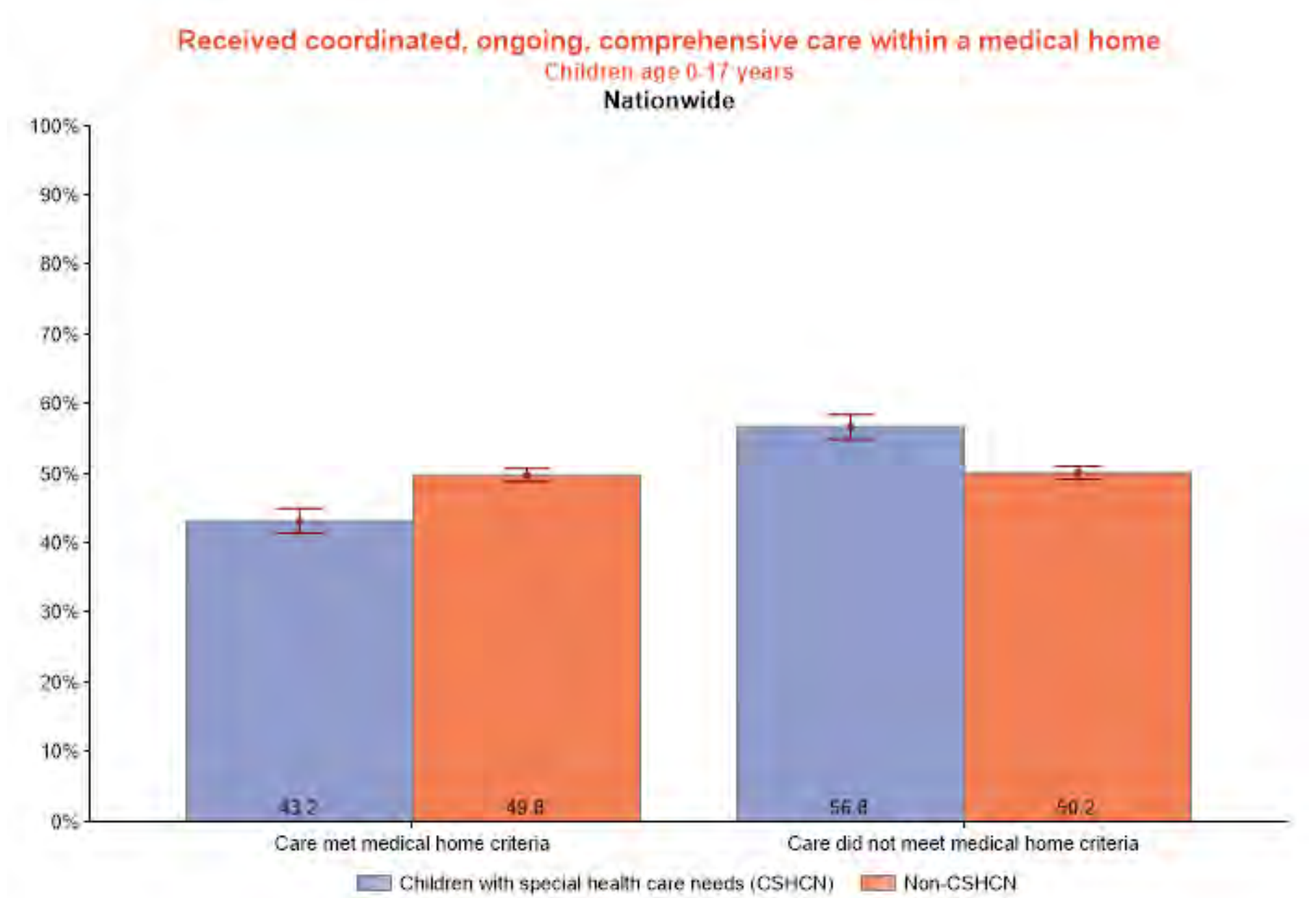
where these can be obtained. Provision of medical information about the patient to the consultant. Evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.

5. Interaction with school and community agencies to be certain that special health needs of the indi-

Medical care of infants, children, and adolescents must sometimes be provided in locations other than physician's offices. However, unless these locations provide all of the services listed above, they do not meet the definition of a medical home. Other venues for children's care include hospital outpatient clinics, school-based and school-linked clinics, community health centers, health department clinics, and others



Source: Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [05/02/19] from www.childhealthdata.org. CAHMI: www.cahmi.org.



Source: Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [05/02/19] from www.childhealthdata.org. CAHMI: www.cahmi.org.

Accelerate.

Upstream.

Levels of Prevention

PRIMARY Prevention	**SECONDARY** Prevention	**TERTIARY** Prevention
An intervention implemented before there is evidence of a disease or injury	An intervention implemented after a disease has begun, but before it is symptomatic.	An intervention implemented after a disease or injury is established

Adapted from: Centers for Disease Control and Prevention. A Framework for Assessing the Effectiveness of Disease and Injury Prevention. MMWR. 1992; 41(RR-3); 001. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/00016403.htm

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

Recommendations for Preventive Pediatric Health Care

Bright Futures/American Academy of Pediatrics

Bright Futures

Each child and family is unique; therefore, these Recommendations for Preventive Pediatric Health Care are designed for the care of children who are receiving competent parenting, have no manifestations of any important health problems, and are growing and developing in a satisfactory fashion. Developmental, psychosocial, and chronic disease issues for children and adolescents may require frequent counseling and treatment visits separate from preventive care visits. Additional visits also may become necessary if circumstances suggest variations from normal.

These recommendations represent a consensus by the American Academy of Pediatrics (AAP) and Bright Futures. The AAP continues to emphasize the great importance of continuity of care in comprehensive health supervision and the need to avoid fragmentation of care.

Refer to the specific guidance by age as listed in the *Bright Futures Guidelines* (Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents.* 4th ed. Elk Grove Village, IL: American Academy of Pediatrics; 2017).

The recommendations in this statement do not indicate an exclusive course of treatment or standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

	INFANCY								EARLY CHILDHOOD							MIDDLE CHILDHOOD						ADOLESCENCE										
AGE[1]	**Prenatal[2]**	**Newborn[3]**	**3-5 d[4]**	**By 1 mo**	**2 mo**	**4 mo**	**6 mo**	**9 mo**	**12 mo**	**15 mo**	**18 mo**	**24 mo**	**30 mo**	**3 y**	**4 y**	**5 y**	**6 y**	**7 y**	**8 y**	**9 y**	**10 y**	**11 y**	**12 y**	**13 y**	**14 y**	**15 y**	**16 y**	**17 y**	**18 y**	**19 y**	**20 y**	**21 y**
HISTORY Initial/Interval	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
MEASUREMENTS																																
Length/Height and Weight		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Head Circumference		●	●	●	●	●	●	●	●	●	●	●																				
Weight for Length		●	●	●	●	●	●	●	●	●	●																					
Body Mass Index[5]												●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Blood Pressure[6]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
SENSORY SCREENING																																
Vision[7]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●	★	●	★	●	★	●	★	★	●	★	★	★	★	★	★
Hearing		●[8]	●[9] →	→	→	★	★	★	★	★	★	★	★	★	●	●	●	★	●	★	●	←	—	●[10]	→	←	●	→	←	—	●	→
DEVELOPMENTAL/BEHAVIORAL HEALTH																																
Developmental Screening[11]								●			●		●																			
Autism Spectrum Disorder Screening[12]											●	●																				
Developmental Surveillance		●	●	●	●	●	●		●	●		●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Psychosocial/Behavioral Assessment[13]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Tobacco, Alcohol, or Drug Use Assessment[14]																						★	★	★	★	★	★	★	★	★	★	★
Depression Screening[15]																							●	●	●	●	●	●	●	●	●	●
Maternal Depression Screening[16]				●	●	●	●																									
PHYSICAL EXAMINATION[17]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
PROCEDURES[18]																																
Newborn Blood		●[19]	●[20] →	→	→																											
Newborn Bilirubin[21]		●																														
Critical Congenital Heart Defect[22]		●																														
Immunization[23]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Anemia[24]						★			●	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★
Lead[25]							★	★	● or ★[26]		★	● or ★[26]		★	★	★	★															
Tuberculosis[27]				★			★		★			★		★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★
Dyslipidemia[28]												★			★		★		★	←	●	→	★	★	★	★	★	←	—	—	●	→
Sexually Transmitted Infections[29]																						★	★	★	★	★	★	★	★	★	★	★
HIV[30]																						★	★	★	★	←	—	●	→	★	★	★
Cervical Dysplasia[31]																																●
ORAL HEALTH[32]							●[33]	●[33]	★		★	★	★	★	★	★	★															
Fluoride Varnish[34]							←	—	—	—	●	—	—	—	—	→																
Fluoride Supplementation[35]							★	★	★		★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★					
ANTICIPATORY GUIDANCE	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●

1. If a child comes under care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up-to-date at the earliest possible time.
2. A prenatal visit is recommended for parents who are at high risk, for first-time parents, and for those who request a conference. The prenatal visit should include anticipatory guidance, pertinent medical history, and a discussion of benefits of breastfeeding and planned method of feeding, per "The Prenatal Visit" (http://pediatrics.aappublications.org/content/124/4/1227.full).
3. Newborns should have an evaluation after birth, and breastfeeding should be encouraged (and instruction and support should be offered).
4. Newborns should have an evaluation within 3 to 5 days of birth and within 48 to 72 hours after discharge from the hospital to include evaluation for feeding and jaundice. Breastfeeding newborns should receive formal breastfeeding evaluation, and their mothers should receive encouragement and instruction, as recommended in "Breastfeeding and the Use of Human Milk" (http://pediatrics.aappublications.org/content/129/3/e827.full). Newborns discharged less than 48 hours after delivery must be examined within 48 hours of discharge, per "Hospital Stay for Healthy Term Newborns" (http://pediatrics.aappublications.org/content/125/2/405.full).
5. Screen, per "Expert Committee Recommendations Regarding the Prevention, Assessment, and Treatment of Child and Adolescent Overweight and Obesity: Summary Report" (http://pediatrics.aappublications.org/content/120/Supplement_4/S164.full).
6. Screening should occur per "Clinical Practice Guideline for Screening and Management of High Blood Pressure in Children and Adolescents" (http://pediatrics.aappublications.org/content/140/3/e20171904). Blood pressure measurement in infants and children with specific risk conditions should be performed at visits before age 3 years.
7. A visual acuity screen is recommended at ages 4 and 5 years, as well as in cooperative 3-year-olds. Instrument-based screening may be used to assess risk at ages 12 and 24 months, in addition to the well visits at 3 through 5 years of age. See "Visual System Assessment in Infants, Children, and Young Adults by Pediatricians" (http://pediatrics.aappublications.org/content/137/1/e20153596) and "Procedures for the Evaluation of the Visual System by Pediatricians" (http://pediatrics.aappublications.org/content/137/1/e20153597).
8. Confirm initial screen was completed, verify results, and follow up, as appropriate. Newborns should be screened, per "Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs" (http://pediatrics.aappublications.org/content/120/4/898.full).
9. Verify results as soon as possible, and follow up, as appropriate.
10. Screen with audiometry including 6,000 and 8,000 Hz high frequencies once between 11 and 14 years, once between 15 and 17 years, and once between 18 and 21 years. See "The Sensitivity of Adolescent Hearing Screens Significantly Improves by Adding High Frequencies" (http://www.jahonline.org/article/S1054-139X(16)00048-3/fulltext).
11. See "Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening" (http://pediatrics.aappublications.org/content/118/1/405.full).
12. Screening should occur per "Identification and Evaluation of Children With Autism Spectrum Disorders" (http://pediatrics.aappublications.org/content/120/5/1183.full).
13. This assessment should be family centered and may include an assessment of child social-emotional health, caregiver depression, and social determinants of health. See "Promoting Optimal Development: Screening for Behavioral and Emotional Problems" (http://pediatrics.aappublications.org/content/135/2/384) and "Poverty and Child Health in the United States" (http://pediatrics.aappublications.org/content/137/4/e20160339).
14. A recommended assessment tool is available at http://crafft.org.
15. Recommended screening using the Patient Health Questionnaire (PHQ)-2 or other tools available in the GLAD-PC toolkit and at http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf.
16. Screening should occur per "Incorporating Recognition and Management of Perinatal and Postpartum Depression Into Pediatric Practice" (http://pediatrics.aappublications.org/content/126/5/1032).
17. At each visit, age-appropriate physical examination is essential, with infant totally unclothed and older children undressed and suitably draped. See "Use of Chaperones During the Physical Examination of the Pediatric Patient" (http://pediatrics.aappublications.org/content/127/5/991.full).
18. These may be modified, depending on entry point into schedule and individual need.

(continued)

KEY: ● = to be performed ★ = risk assessment to be performed with appropriate action to follow, if positive ←●→ = range during which a service may be provided

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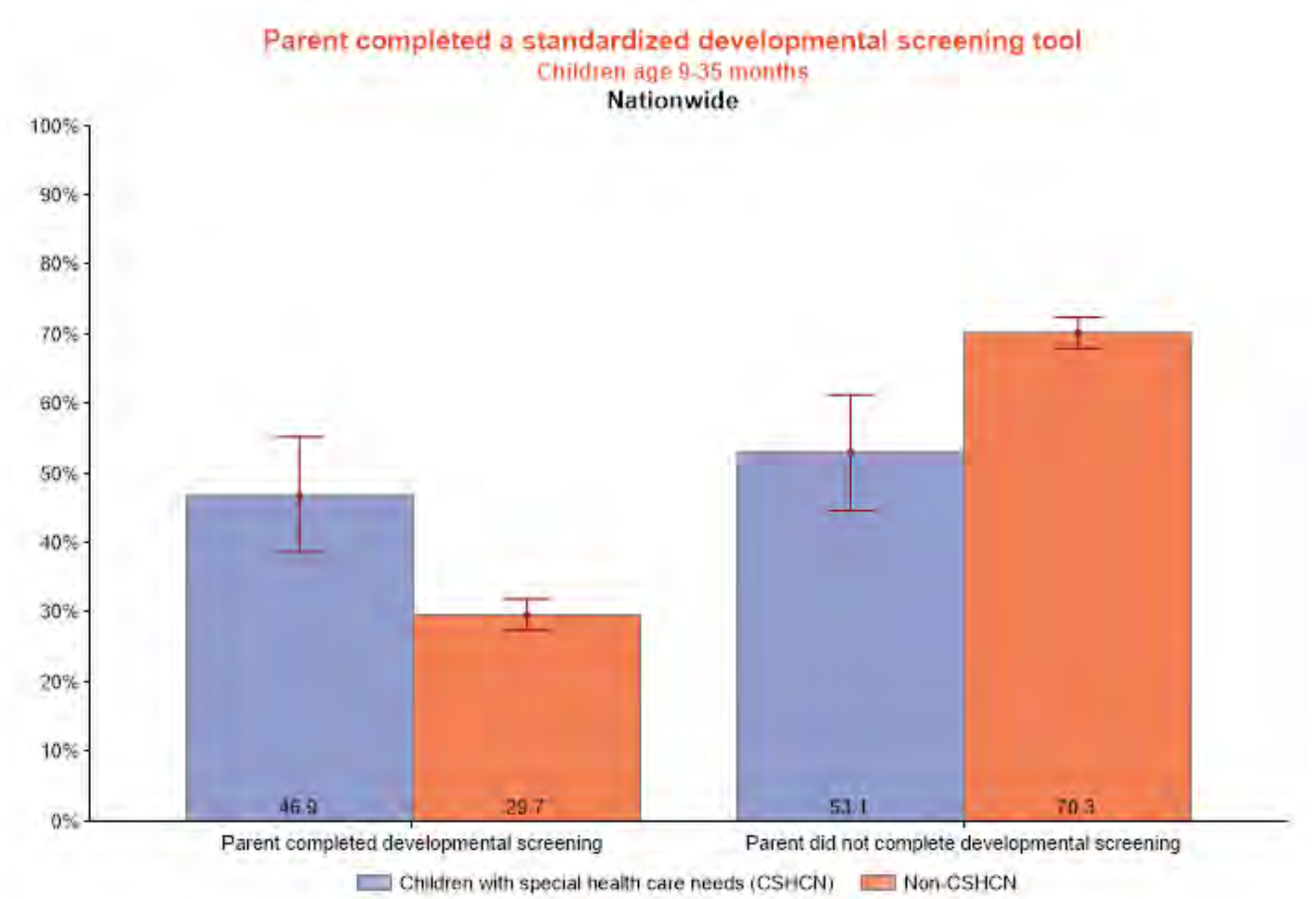

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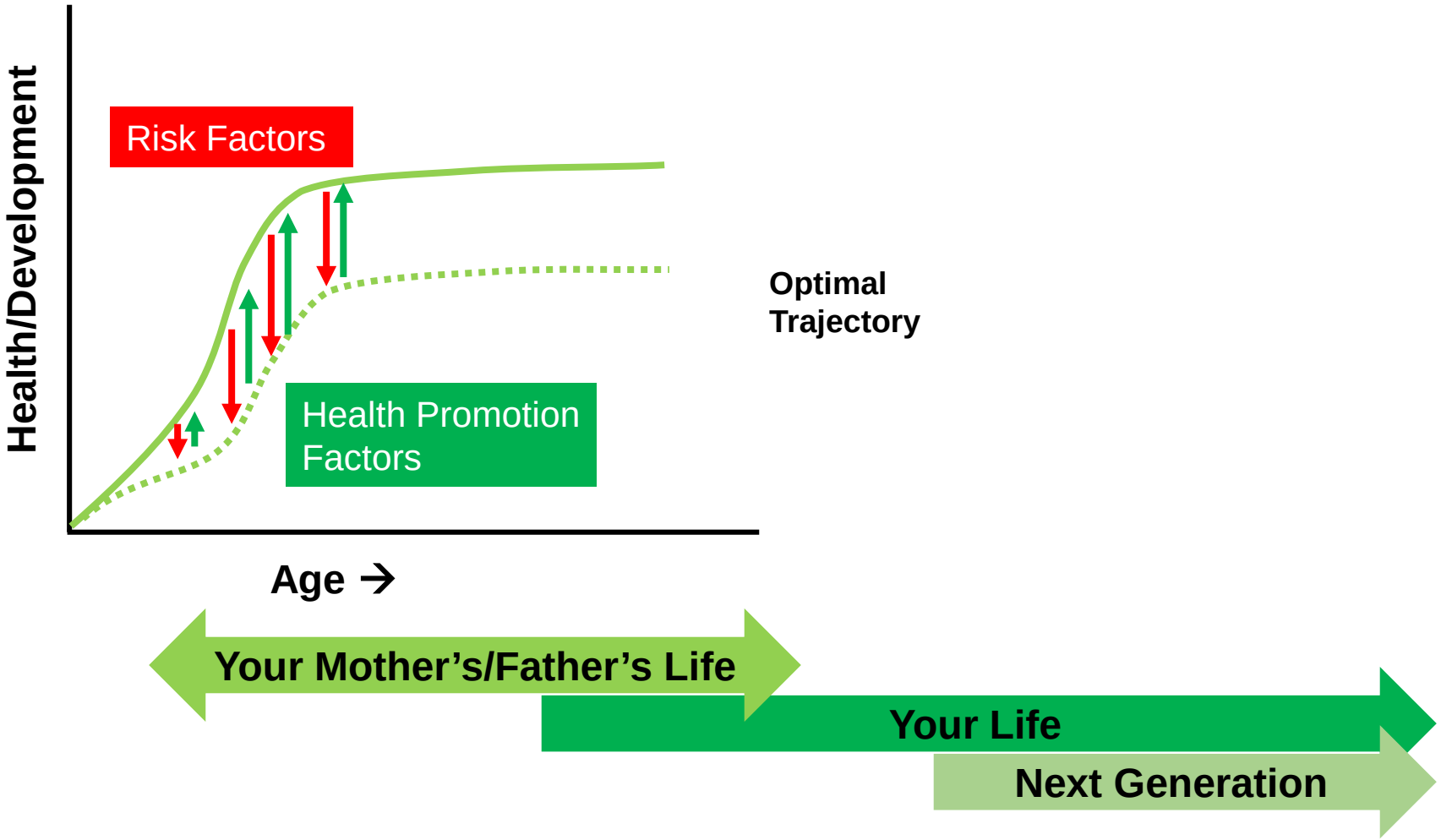
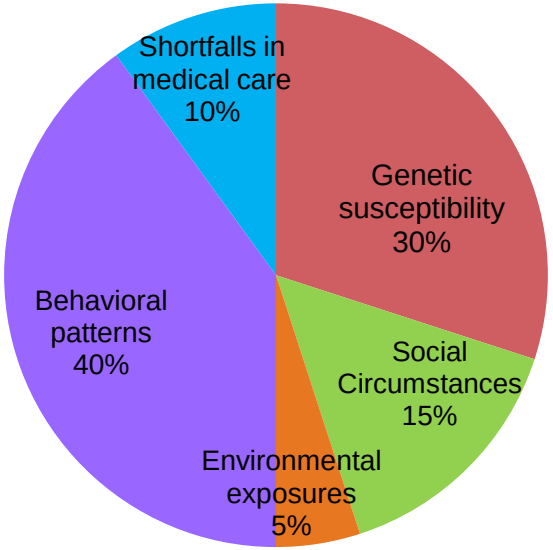
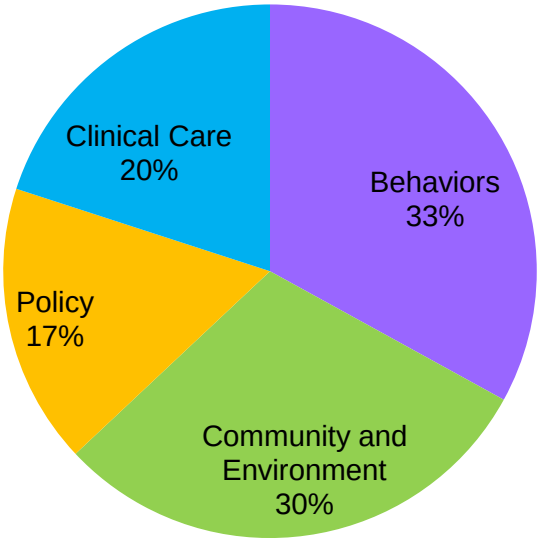
Life Course Model



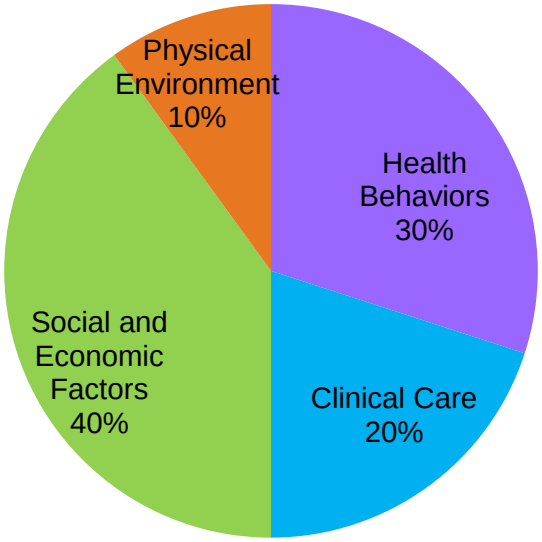
Adapted from the Life Course Toolkit by CityMatCH. Available at: http://www.citymatch.org/projects/mch-life-course-toolbox .
Based on: Lu, M.C. & Halfon, N. Matern Child Health J (2003) 7: 13

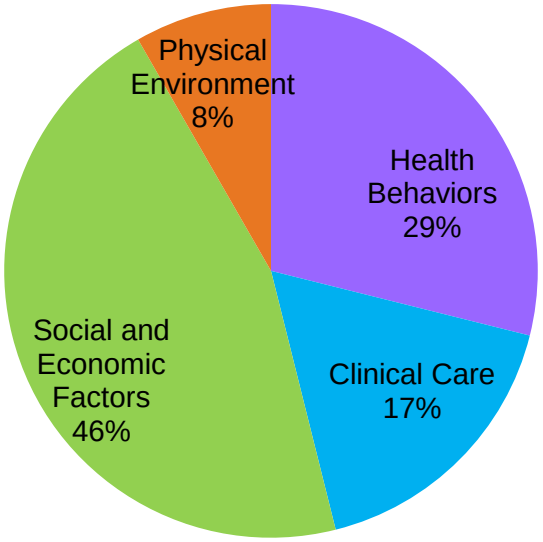
What Determines Health?





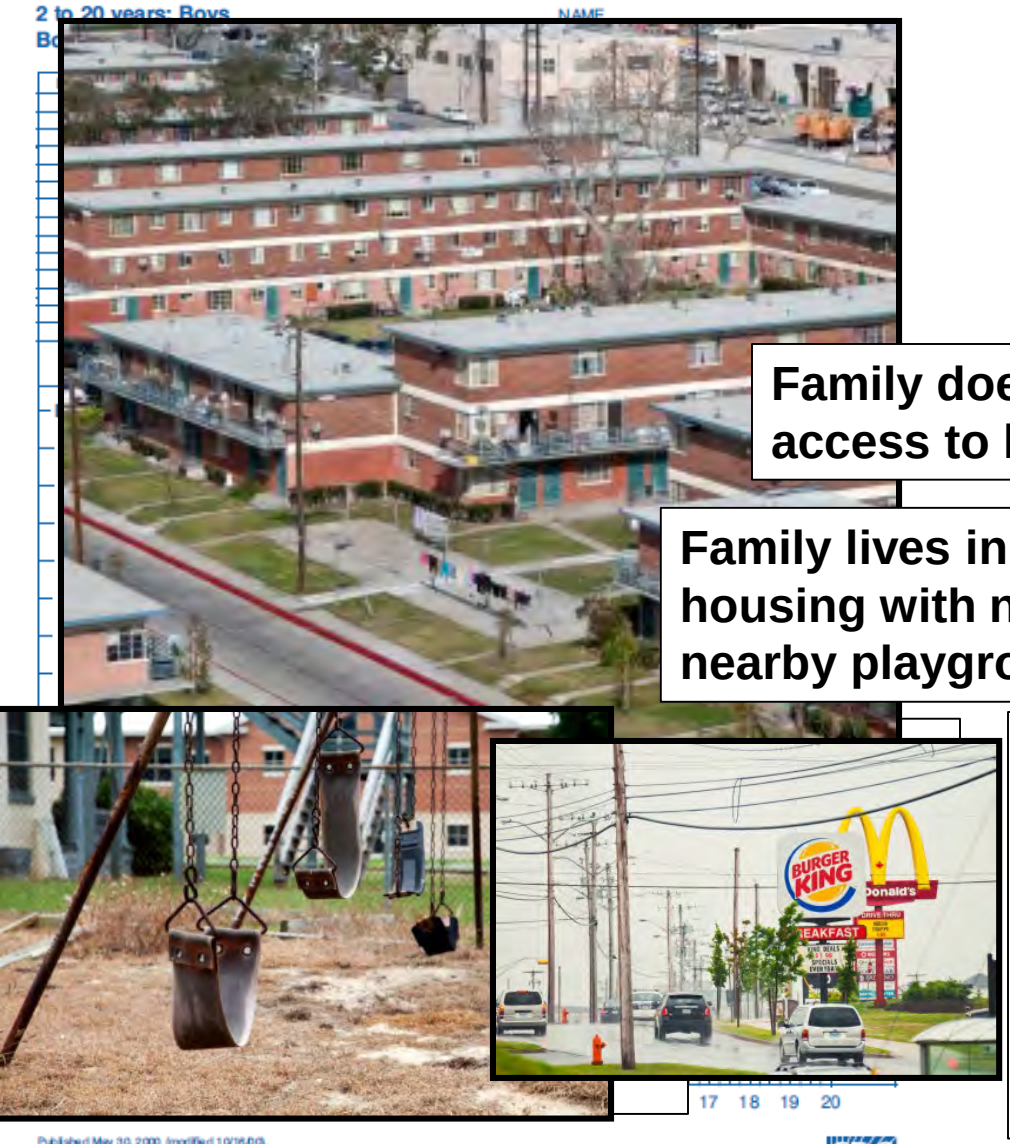
Health <u>care</u> accounts for only 10-20% of overall health





Upper left: McGinnis JM, Williams-Russo P, Knickman JR. The case for more active policy attention to health promotion. Health Aff. 2002; 21(2):78-93. **Lower left**: Remington PL, Catlin BB, Gennusko KP. The County Health Rankings: rationale and methods. Popul Health Metr. 2014; 13:11. **Upper right**: American's Health Rankings. www.americashealthrankings.org. **Lower right**: Park H et al. Relative Contributions of a Set of Health Factors to Selected Health Outcomes Am J Prev Med 2015;49(6):961–969.

A Clinical Example: Obesity



- Why isn't this patient's weight status improving?

Family does not have ready access to healthy food

School does not have funding for PE teacher

Family lives in public housing with no yard or nearby playground

Father is also obese and limits physical activity time with child

Single mother works two jobs and has limited time for shopping and preparing healthy food

School does not have large enough refrigerator for storing fresh fruits/vegetables

Accelerate.

Upstream.

Together.

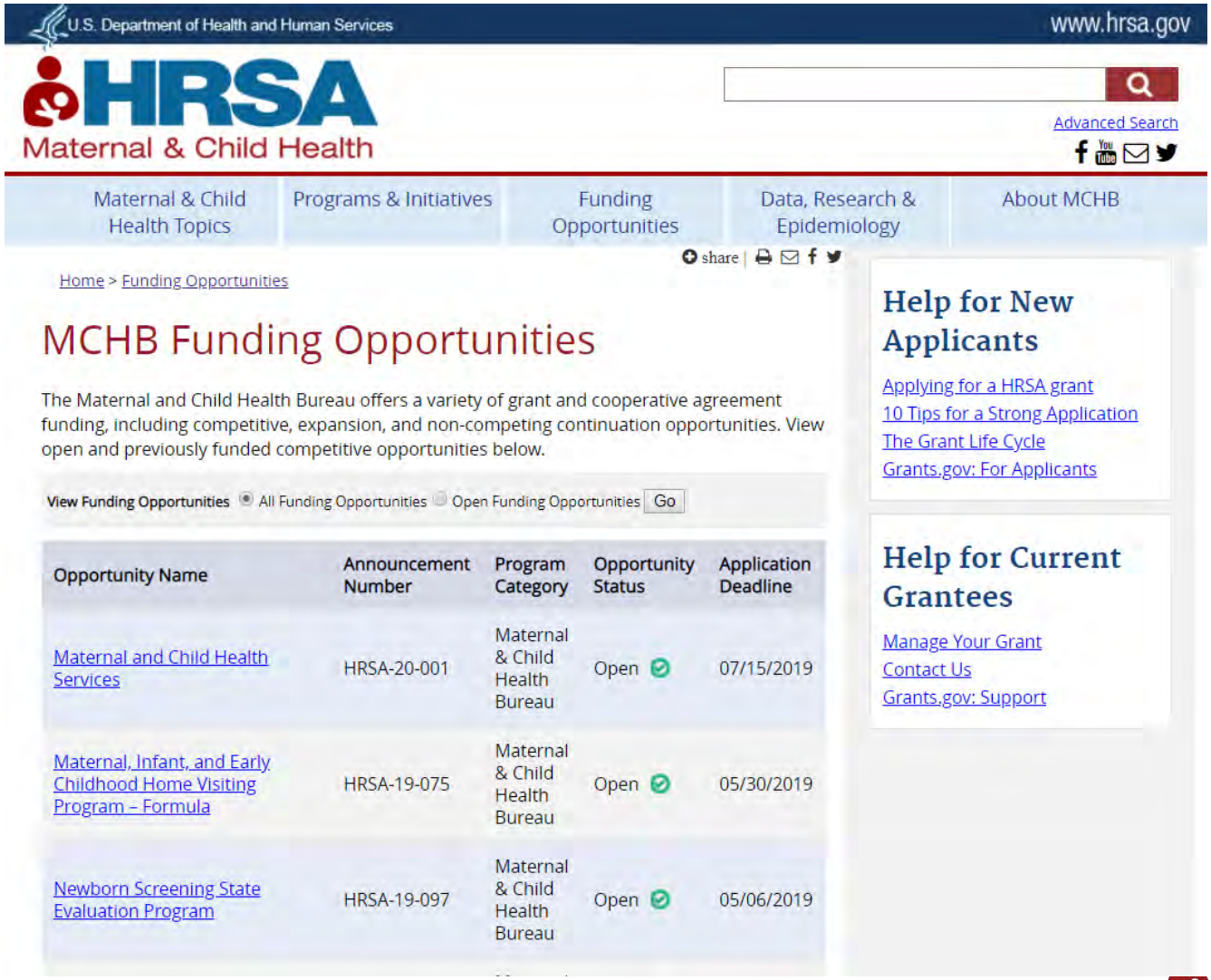
Ways to Get Involved

Get to Know Your Title V Leadership
https://mchb.tvisdata.hrsa.gov/

MCH Block Grant
Five Year Needs Assessments

- Next one due July 2020!
- Opportunity to provide input on needs and capacity related to child health in your state
- Influence MCH Block Grant priorities for next five years
- **Contact State MCH Director (contact information on TVIS)**

MCHB Funding Opportunities



Examples of Family Engagement in MCHB Funding Opportunities

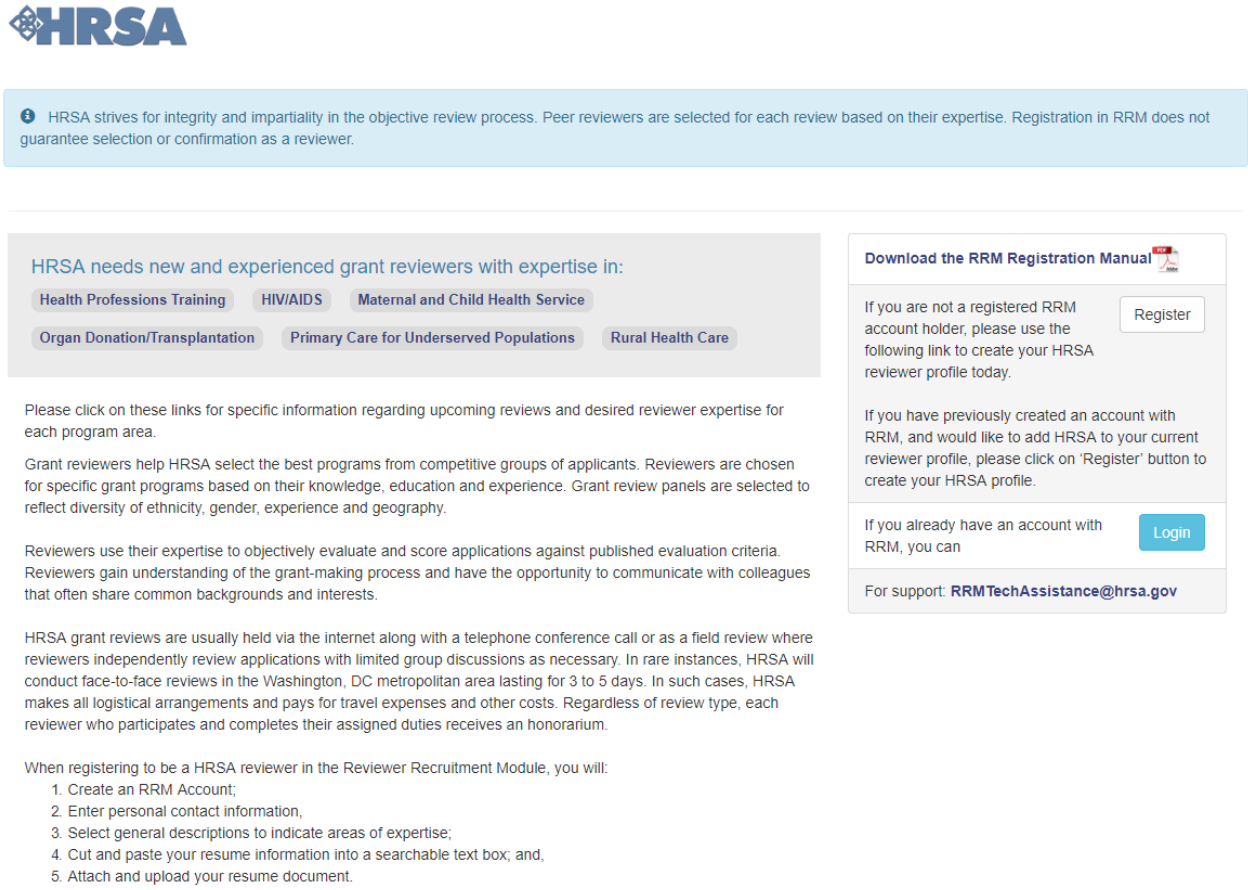
"…The curriculum must also include content about family/youth-centered care, as appropriate, that assures the health and well-being of clients and their families through a respectful family-professional partnership. It should honor the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family Centered Care is the standard of practice which results in high quality services."
MCH Nutrition Training Program

"…Promote patient and family engagement as partners in care by having patients and/or family members on workgroups and advisory groups and by collaborating with the National Genetics Education and Family Support Center."
Regional Genetics Network Grant

"…EMSC family representatives play a unique role in program success...The EMSC FAN representatives foster partnerships within their communities, and the consumers' perspective to improve the delivery of patient care, and promote the integration of family- and patient-centered practices within health care systems."
EMSC State Partnership Grant

HRSA Grant Reviewers

https://www.hrsa.gov/grants/reviewers/index.html



HRSA

HRSA strives for integrity and impartiality in the objective review process. Peer reviewers are selected for each review based on their expertise. Registration in RRM does not guarantee selection or confirmation as a reviewer.

HRSA needs new and experienced grant reviewers with expertise in:

Health Professions Training | HIV/AIDS | Maternal and Child Health Service | Organ Donation/Transplantation | Primary Care for Underserved Populations | Rural Health Care

Please click on these links for specific information regarding upcoming reviews and desired reviewer expertise for each program area.

Grant reviewers help HRSA select the best programs from competitive groups of applicants. Reviewers are chosen for specific grant programs based on their knowledge, education and experience. Grant review panels are selected to reflect diversity of ethnicity, gender, experience and geography.

Reviewers use their expertise to objectively evaluate and score applications against published evaluation criteria. Reviewers gain understanding of the grant-making process and have the opportunity to communicate with colleagues that often share common backgrounds and interests.

HRSA grant reviews are usually held via the internet along with a telephone conference call or as a field review where reviewers independently review applications with limited group discussions as necessary. In rare instances, HRSA will conduct face-to-face reviews in the Washington, DC metropolitan area lasting for 3 to 5 days. In such cases, HRSA makes all logistical arrangements and pays for travel expenses and other costs. Regardless of review type, each reviewer who participates and completes their assigned duties receives an honorarium.

When registering to be a HRSA reviewer in the Reviewer Recruitment Module, you will:

1. Create an RRM Account;
2. Enter personal contact information,
3. Select general descriptions to indicate areas of expertise;
4. Cut and paste your resume information into a searchable text box; and,
5. Attach and upload your resume document.

Download the RRM Registration Manual

If you are not a registered RRM account holder, please use the following link to create your HRSA reviewer profile today. Register

If you have previously created an account with RRM, and would like to add HRSA to your current reviewer profile, please click on 'Register' button to create your HRSA profile.

If you already have an account with RRM, you can Login

For support: RRMTechAssistance@hrsa.gov

MCHB Grand Challenges

HRSA Maternal & Child Health

Challenges

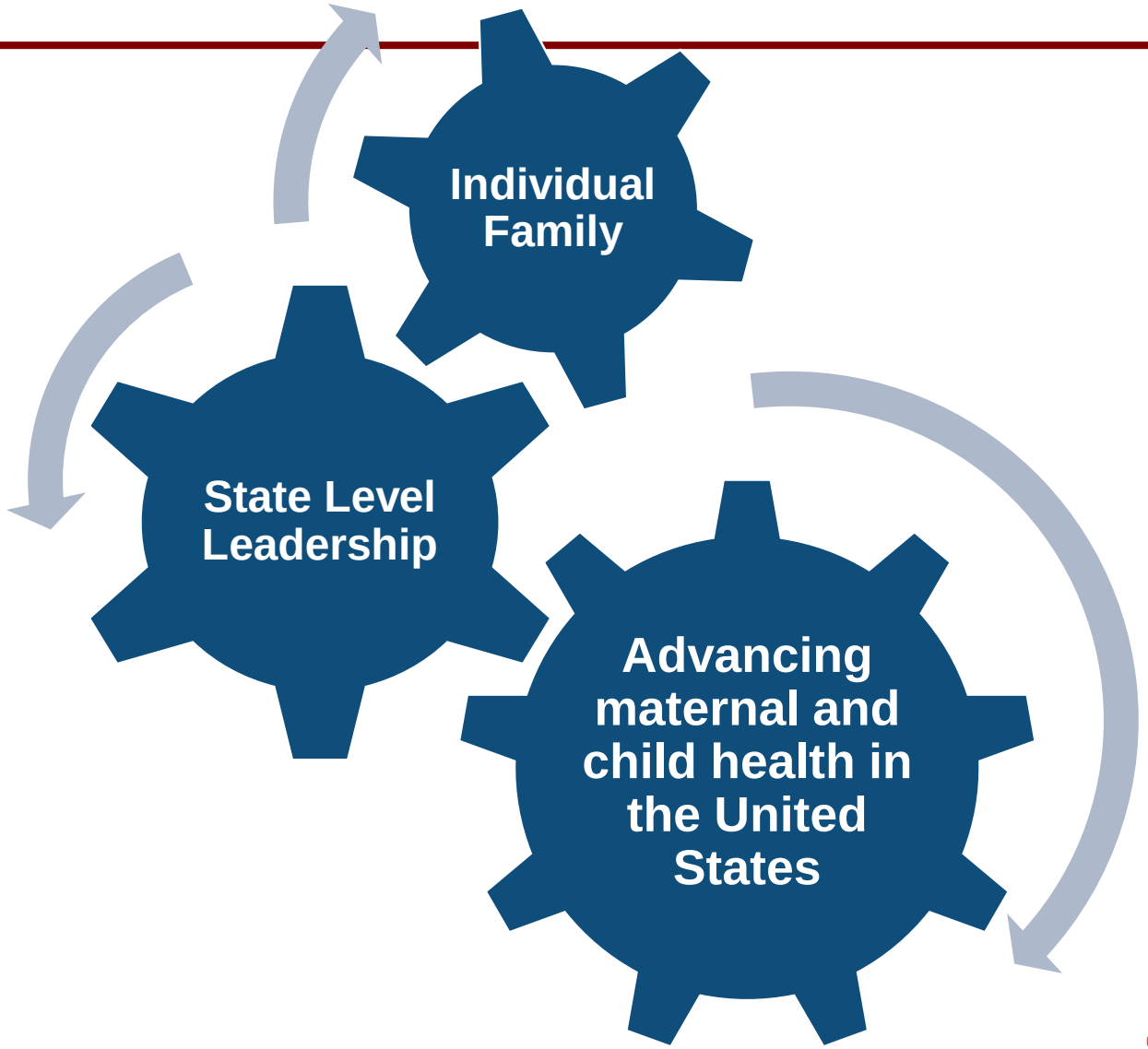
Remote Pregnancy Monitoring

Care Coordination for CSHCN

Preventing Childhood Obesity

Addressing Opioid Use Disorder in Pregnant Women and New Moms

Keep Doing What You're Doing!



HRSA Maternal & Child Health

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