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

Michael D. Warren, MD MPH FAAP
Associate Administrator, Maternal and Child Health Bureau (MCHB)
Health Resources and Services Administration (HRSA)
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
1912: Founding of the Children’s Bureau

“…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
1981: Creation of the MCH Block Grant

- Maternal and Child Health Services
- Services for Children with Special Health Needs
- Supplemental Security Income for Children with Disabilities
- Lead-based Paint Poisoning Prevention Programs
- Genetic Disease Programs
- Sudden Infant Death Syndrome Programs
- Hemophilia Treatment Centers
- Adolescent Pregnancy Prevention Grants

Title V Maternal and Child Health Services Block Grant
Today’s Maternal and Child Health Bureau

MCHB Program Areas

- Services for Children with Special Healthcare Needs
- State & Community Health
- Home Visiting & Early Childhood Services
- Healthy Start & Perinatal Services
- Epidemiology & Research
- MCH Workforce Development
- Child, Adolescent and Family Health
Mission:
Improve the health of America’s mothers, children, and families.
Department of Health and Human Services (Operating Divisions)

<table>
<thead>
<tr>
<th>Department of Health and Human Services (DHHS)</th>
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<tbody>
<tr>
<td>Administration for Children and Families (ACF)</td>
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<td>National Institutes of Health (NIH)</td>
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<td>Substance Abuse and Mental Health Services Administration (SAMHSA)</td>
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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
### Maternal and Child Health Bureau

**FY 2019 Total Budget: $1.33 billion**

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<thead>
<tr>
<th>Maternal and Child Health Bureau Programs</th>
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<tr>
<td>Maternal and Child Health Block Grant</td>
<td>$677.7</td>
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<td>Maternal, Infant and Early Childhood Home Visiting</td>
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<td>Family-to-Family Health Information Centers</td>
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<td>Screening and Treatment for Maternal Depression</td>
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<tr>
<td>Sickle Cell service Demonstration Program</td>
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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 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

Health Insurance Coverage Among CSHCN at Time of Survey, 2009–10

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”
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 and trust. Traditionally, this role has 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 following:

1. Medical care should be accessible, continuous, comprehensive, family centered, coordinated, and compassionate.
2. Physician-delivered care must be directed by a well-trained pediatrician.
3. Physician-delivered care should be the primary source of medical care for the child.
4. Provision of medical information about the patient to the consultant.
5. Interaction with school and community agencies to be certain that special health needs of the individual child are met.

Database information should include detailed history of the child, including information about hospitalizations. This record should be accessible, but confidentiality must be assured.

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.
Received coordinated, ongoing, comprehensive care within a medical home

Children age 0-17 years

Nationwide

Received coordinated, ongoing, comprehensive care within a medical home
Children age 0-17 years
Nationwide

Accelerate.

Upstream.
# Levels of Prevention

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<th>PRIMARY Prevention</th>
<th>SECONDARY Prevention</th>
<th>TERTIARY Prevention</th>
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<tbody>
<tr>
<td>An intervention implemented before there is evidence of a disease or injury</td>
<td>An intervention implemented after a disease has begun, but before it is symptomatic.</td>
<td>An intervention implemented after a disease or injury is established</td>
</tr>
</tbody>
</table>

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](http://www.cdc.gov/mmwr/preview/mmwrhtml/00016403.htm)
# Recommendations for Preventive Pediatric Health Care

**Bright Futures/American Academy of Pediatrics**

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 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.

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**KEY**

- ○: To be performed
- ●: Risk assessment to be performed with appropriate action to follow, if positive
- □: Procedure to be performed
- °: Range during which a service may be provided

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**Notes:**

1. A written history should be obtained at the first time of any visit and at any time new information is needed at the same age. The schedule should be tailored to accommodate the child's age.

2. A complete physical examination of the child is recommended at ages 4 and 5 years, as well as at intervals thereafter. Instrument-based screening should be performed as soon as possible after age 5 years.

3. Neonates should have an evaluation at birth, and breastfeeding should be encouraged. (Instructions for breastfeeding should be offered.)

4. Newborns should have an evaluation within 1 to 3 days of birth and within 48 to 72 hours after discharge from the hospital to include evaluation for feeding and jaundice. Breastfeeding should be encouraged.

5. Newborns should have an exam within 1 to 3 days of birth and within 48 to 72 hours after discharge from the hospital to include evaluation for feeding and jaundice. Breastfeeding should be encouraged.

6. Contraindicated or limited criteria screening may occur in some cases. (See the Bright Futures Guidelines for more information.)

7. Screen for autism spectrum disorder at age 6 and 7 years. Screen for autism at age 5 years.

8. Screen for depression at age 12 and 24 months.

9. Screen for anxiety at age 36 months.

10. Screen for mental health at age 48 months.

11. Screen for developmental disorders at age 48 months.

12. Screening should occur for "Identification and Evaluation of Children With Autism Spectrum Disorders." (See the Bright Futures Guidelines for more information.)

13. This assessment should be tailored to the individual child and may include an assessment of child social-emotional health, caregiver depression, and social development of health. See "Addressing Social and Emotional Problems" (see the Bright Futures Guidelines for more information.)

14. A recommended assessment tool is available at the AAP website.

15. Recommended screening using the Patient Health Questionnaire (PHQ-2) or other tools available in the GLAD PC manual and/or www.brightfutures.aap.org/contests/2017-2018-Health

16. Screen for depression at age 12 and 24 months.

17. Screen for anxiety at age 36 months.

18. Screen for mental health at age 48 months.

19. Screen for developmental disorders at age 48 months.

20. Screen for autism spectrum disorder at age 6 and 7 years.
Parent completed a standardized developmental screening tool

Children age 9-35 months

Nationwide

Parent completed developmental screening

<table>
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<tr>
<th>Description</th>
<th>CSHCN</th>
<th>Non-CSHCN</th>
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<tbody>
<tr>
<td>Children with special health care needs (CSHCN)</td>
<td>46.9%</td>
<td>29.7%</td>
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<tr>
<td>Non-CSHCN</td>
<td>53.1%</td>
<td>70.3%</td>
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Life Course Model

- Risk Factors
- Health Promotion Factors
- Optimal Trajectory

Adapted from the Life Course Toolkit by CityMatCH. Available at: http://www.citymatch.org/projects/mch-life-course-toolbox.
What Determines Health?

Health care accounts for only 10-20% of overall health

A Clinical Example: Obesity

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

- Pediatrician didn’t talk about physical activity or nutrition
- Pediatrician didn’t bring child in for office visits often enough
- Single mother works two jobs and has limited time for shopping and preparing healthy food
- Family does not have ready access to healthy food
- Family lives in public housing with no yard or nearby playground
- Father is also obese and limits physical activity time with child
- 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/](https://mchb.tvisdata.hrsa.gov/)

### State Contacts: Oregon

Search by State or by Region for contact information on MCH Directors, CSHCN Directors, and State Family or Youth Leaders.

#### Oregon

<table>
<thead>
<tr>
<th><strong>MCH Director</strong></th>
<th><strong>CSHCN Director</strong></th>
<th><strong>State Family or Youth Leader</strong></th>
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<tbody>
<tr>
<td>Cate Wilcox, MPH</td>
<td>Benjamin Hoffman, MD</td>
<td>Tamara Bakewell</td>
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<tr>
<td>Title V Director, MCH Manager</td>
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<td>800 NE Oregon St, Ste 825</td>
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<tr>
<td>Portland, OR 97232</td>
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<tr>
<td>(971) 673-0299</td>
<td>Title V CYSHCN Director</td>
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<tr>
<td><a href="mailto:cate.s.wilcox@state.or.us">cate.s.wilcox@state.or.us</a></td>
<td>707 SW Gaines Street</td>
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<td>Portland, OR 97239</td>
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<tr>
<td></td>
<td>(503) 494-2214</td>
<td>Family Involvement Coordinator</td>
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<td><a href="mailto:hoffmanb@ohsu.edu">hoffmanb@ohsu.edu</a></td>
<td>707 SW Gaines St</td>
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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

The Maternal and Child Health Bureau offers a variety of grant and cooperative agreement funding, including competitive, expansion, and non-competing continuation opportunities. View open and previously funded competitive opportunities below.

<table>
<thead>
<tr>
<th>Opportunity Name</th>
<th>Announcement Number</th>
<th>Program Category</th>
<th>Opportunity Status</th>
<th>Application Deadline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal and Child Health Services</td>
<td>HRSA-20-001</td>
<td>Maternal &amp; Child Health Bureau</td>
<td>Open</td>
<td>07/15/2019</td>
</tr>
<tr>
<td>Maternal, Infant, and Early Childhood Home Visiting Program – Formula</td>
<td>HRSA-19-075</td>
<td>Maternal &amp; Child Health Bureau</td>
<td>Open</td>
<td>05/30/2019</td>
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<tr>
<td>Newborn Screening State Evaluation Program</td>
<td>HRSA-19-097</td>
<td>Maternal &amp; Child Health Bureau</td>
<td>Open</td>
<td>05/06/2019</td>
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</tbody>
</table>

#### Help for New Applicants
- Applying for a HRSA grant
- 10 Tips for a Strong Application
- The Grant Life Cycle
- Grants.gov: For Applicants

#### Help for Current Grantees
- Manage Your Grant
- Contact Us
- Grants.gov: Support
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 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.

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

For support: RRMTechAssistance@hrsa.gov
MCHB Grand 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!

State Level Leadership

Individual Family

Advancing maternal and child health in the United States
Connect with HRSA

To learn more about our agency, visit

www.HRSA.gov

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