Reflections, Outcomes, and Impact

Progress on Pediatric Medical Home Implementation

2013-2018
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forward from W Carl Cooley, MD, FAAP</td>
<td>1</td>
</tr>
<tr>
<td>–Chairperson, Medical Home Implementation Project Advisory Committee</td>
<td></td>
</tr>
<tr>
<td>About the National Center for Medical Home Implementation</td>
<td>3</td>
</tr>
<tr>
<td>Significant Accomplishments</td>
<td>5</td>
</tr>
<tr>
<td>Enhancing Sustainability through Partnerships</td>
<td>8</td>
</tr>
<tr>
<td>The Path Forward</td>
<td>11</td>
</tr>
<tr>
<td>Tools and Resources</td>
<td>14</td>
</tr>
</tbody>
</table>

“My vision from the start has always been to broaden the base from my busy primary care pediatric practice and 'get involved' voluntarily to develop an integrated system of care in our state and nation. It has been a long journey of successes and failures; but I have tried to persevere through the political climate for the sake of children and families. It has always been a ‘team effort.’”

–Calvin CJ Sia, MD, FAAP
The National Center for Medical Home Implementation is a cooperative agreement between the American Academy of Pediatrics and the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA) of the United States (US) Department of Health and Human Services (HHS) under grant number U43MC09134. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the US government.

MEDICAL HOME IMPLEMENTATION PROJECT ADVISORY COMMITTEE, 2017-2018

William Carl Cooley, MD, FAAP (Chairperson)
Richard C Antonelli, MD, MS, FAAP
Joan Jeung, MD, MS, FAAP
Thomas S Klitzner, MD, PhD, FAAP
Jennifer L Lail, MD, FAAP
Mary M Erickson, DNP, RN, PNP
Deborah Garneau, MA
Amy Mullins, MD
William E Schwab, MD
Christopher J Stille, MD, MPH, FAAP
Beverly Baker
Virginia Keane, MD, FAAP (liaison from the AAP Council of Community Pediatrics)
Mark Hudak, MD, FAAP (liaison from the AAP Committee on Child Health Financing)
Marie Y Mann, MD, MPH, FAAP (Maternal and Child Health Bureau)

CHAIRPERSON EMERITUS

Calvin Sia, MD, FAAP

PAST PROJECT ADVISORY COMMITTEE MEMBERS AND LIAISONS, 2013-2017

Lee Partridge
Debra Waldron, MD, MPH, FAAP
Nora Wells, MSED
Linda Lindeke, PhD, RN, CNP
Colleen Kraft, MD, FAAP

NATIONAL CENTER STAFF

Michelle Zajac Esquivel, MPH
Hope Barrett, MPH
Christina Boothby, MPA
Müge Chavdar, MPH
Jamie Doucet, MPH
Alex Kuznetsov, RD
Bethany Mlochoch
Karla Palmer
The National Center for Medical Home Implementation (NCMHI or National Center)—a cooperative agreement between the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration and the American Academy of Pediatrics (AAP)—is pleased to reflect on progress and accomplishments over the last five years. For over fifteen years, the AAP has been proud to serve as the leading technical assistance center—supported by the MCHB—for the advancement and implementation of the family-centered pediatric medical home.

We have come a long way! As outlined in the goals of the cooperative agreement (listed below) family engagement, systems change, and strategic partnerships were a major focus of the efforts of the National Center throughout the cooperative agreement.

In Years 1-3 (2013-2016) of the cooperative agreement, resource and project planning/development were the priority—supporting clinicians and families in the implementation and advancement of pediatric medical home and family-centered care. During this time, we looked broadly and developed tools and resources relevant to all children and families.

In Years 4-5 (2017-2018) of the cooperative agreement, however, the focus and prioritization for the National Center shifted to keep up with the ever-changing healthcare environment. An enhanced focus on children and youth with special health care needs (CYSHCN) was prioritized, with particular emphasis on the health and well-being of children who are medically vulnerable and medically underserved.

As a result, the National Center focused more broadly on systems integration and systems of care. We concentrated on building relationships with Maternal and Child Health Title V / Children and Youth with Special Health Care Needs programs through a partnership with the Association of Maternal and Child Health Programs and aligning efforts around policy development for CYSHCN through partnership with the National Academy for State Health Policy. However, these are only two of the many valuable collaborative relationships that the National Center cultivated over the last five years.
I hope you have had opportunities to utilize the wide range of tools and resources the NCMHI has developed. The sentinel projects highlighted throughout this report have supported the goals set forth by the NCMHI since 2013; these goals include the following:

- Lead and facilitate the acceptance, implementation, and spread of family-centered medical home, thereby optimizing the health of children with and without special health care needs over the life course.
- Support continued innovation in strategies and models for family-professional partnerships and family-centered care at the practice, organization, and system levels.
- Advance system changes and new initiatives at the community, state, and national levels to support family-centered medical home implementation for all children and youth.
- Expand and enhance activities that document the effectiveness of evidence-based, family-centered medical home that will result in their broad dissemination and sustainable use.

I have had the privilege and pleasure of serving as the chairperson for the Medical Home Implementation Project Advisory Committee throughout the project period and would be remiss to not thank those whose great contributions have led to an impactful National Center both in the past and during the current five-year cycle. First and foremost, I must acknowledge my mentor and predecessor—Dr Cal Sia—a pioneer in family-centered care and pediatric medical home implementation; he has supported this endeavor since the beginning. I also would like to recognize the NCMHI Maternal and Child Health Bureau project officer, Dr Marie Mann. Dr Mann’s guidance and leadership have been instrumental in the success the National Center has enjoyed. To my fellow Medical Home Implementation Project Advisory Committee members, past and present—thank you for your tireless and thoughtful contributions and support in aiding the NCMHI staff to produce effective, practical, and meaningful education, tools, and resources.

Lastly, I want to thank the American Academy of Pediatrics and the NCMHI staff for their hard work and dedication to ensuring that care provided to children and families is done within the context of the family-centered medical home model. I am confident that children’s health and well-being have improved and will continue to improve as a result of these efforts.

—I hope you have had opportunities to utilize the wide range of tools and resources the NCMHI has developed. The sentinel projects highlighted throughout this report have supported the goals set forth by the NCMHI since 2013; these goals include the following:

- Lead and facilitate the acceptance, implementation, and spread of family-centered medical home, thereby optimizing the health of children with and without special health care needs over the life course.
- Support continued innovation in strategies and models for family-professional partnerships and family-centered care at the practice, organization, and system levels.
- Advance system changes and new initiatives at the community, state, and national levels to support family-centered medical home implementation for all children and youth.
- Expand and enhance activities that document the effectiveness of evidence-based, family-centered medical home that will result in their broad dissemination and sustainable use.

I have had the privilege and pleasure of serving as the chairperson for the Medical Home Implementation Project Advisory Committee throughout the project period and would be remiss to not thank those whose great contributions have led to an impactful National Center both in the past and during the current five-year cycle. First and foremost, I must acknowledge my mentor and predecessor—Dr Cal Sia—a pioneer in family-centered care and pediatric medical home implementation; he has supported this endeavor since the beginning. I also would like to recognize the NCMHI Maternal and Child Health Bureau project officer, Dr Marie Mann. Dr Mann’s guidance and leadership have been instrumental in the success the National Center has enjoyed. To my fellow Medical Home Implementation Project Advisory Committee members, past and present—thank you for your tireless and thoughtful contributions and support in aiding the NCMHI staff to produce effective, practical, and meaningful education, tools, and resources.

Lastly, I want to thank the American Academy of Pediatrics and the NCMHI staff for their hard work and dedication to ensuring that care provided to children and families is done within the context of the family-centered medical home model. I am confident that children’s health and well-being have improved and will continue to improve as a result of these efforts.

—I hope you have had opportunities to utilize the wide range of tools and resources the NCMHI has developed. The sentinel projects highlighted throughout this report have supported the goals set forth by the NCMHI since 2013; these goals include the following:

- Lead and facilitate the acceptance, implementation, and spread of family-centered medical home, thereby optimizing the health of children with and without special health care needs over the life course.
- Support continued innovation in strategies and models for family-professional partnerships and family-centered care at the practice, organization, and system levels.
- Advance system changes and new initiatives at the community, state, and national levels to support family-centered medical home implementation for all children and youth.
- Expand and enhance activities that document the effectiveness of evidence-based, family-centered medical home that will result in their broad dissemination and sustainable use.

I have had the privilege and pleasure of serving as the chairperson for the Medical Home Implementation Project Advisory Committee throughout the project period and would be remiss to not thank those whose great contributions have led to an impactful National Center both in the past and during the current five-year cycle. First and foremost, I must acknowledge my mentor and predecessor—Dr Cal Sia—a pioneer in family-centered care and pediatric medical home implementation; he has supported this endeavor since the beginning. I also would like to recognize the NCMHI Maternal and Child Health Bureau project officer, Dr Marie Mann. Dr Mann’s guidance and leadership have been instrumental in the success the National Center has enjoyed. To my fellow Medical Home Implementation Project Advisory Committee members, past and present—thank you for your tireless and thoughtful contributions and support in aiding the NCMHI staff to produce effective, practical, and meaningful education, tools, and resources.

Lastly, I want to thank the American Academy of Pediatrics and the NCMHI staff for their hard work and dedication to ensuring that care provided to children and families is done within the context of the family-centered medical home model. I am confident that children’s health and well-being have improved and will continue to improve as a result of these efforts.

—I hope you have had opportunities to utilize the wide range of tools and resources the NCMHI has developed. The sentinel projects highlighted throughout this report have supported the goals set forth by the NCMHI since 2013; these goals include the following:

- Lead and facilitate the acceptance, implementation, and spread of family-centered medical home, thereby optimizing the health of children with and without special health care needs over the life course.
- Support continued innovation in strategies and models for family-professional partnerships and family-centered care at the practice, organization, and system levels.
- Advance system changes and new initiatives at the community, state, and national levels to support family-centered medical home implementation for all children and youth.
- Expand and enhance activities that document the effectiveness of evidence-based, family-centered medical home that will result in their broad dissemination and sustainable use.

I have had the privilege and pleasure of serving as the chairperson for the Medical Home Implementation Project Advisory Committee throughout the project period and would be remiss to not thank those whose great contributions have led to an impactful National Center both in the past and during the current five-year cycle. First and foremost, I must acknowledge my mentor and predecessor—Dr Cal Sia—a pioneer in family-centered care and pediatric medical home implementation; he has supported this endeavor since the beginning. I also would like to recognize the NCMHI Maternal and Child Health Bureau project officer, Dr Marie Mann. Dr Mann’s guidance and leadership have been instrumental in the success the National Center has enjoyed. To my fellow Medical Home Implementation Project Advisory Committee members, past and present—thank you for your tireless and thoughtful contributions and support in aiding the NCMHI staff to produce effective, practical, and meaningful education, tools, and resources.

Lastly, I want to thank the American Academy of Pediatrics and the NCMHI staff for their hard work and dedication to ensuring that care provided to children and families is done within the context of the family-centered medical home model. I am confident that children’s health and well-being have improved and will continue to improve as a result of these efforts.
The goal of the NCMHI is to ensure all children—particularly those with special health care needs—have access to a medical home. To ensure the provision of health care services are accessible, family-centered, continuous, comprehensive, coordinated, and culturally effective for children, the National Center has reached its goal by implementing the following strategies:

- Development and distribution of tools and resources for medical home implementation
- Provision of technical assistance and support to practices, clinicians, families, communities, and states
- Implementation of pilot projects focused on core components and functions of the medical home
- Collaboration with local, state, and national partners to facilitate partnership and medical home system change

In 2013, the National Center began a formal partnership with the Healthy Tomorrows Partnership for Children Program (HTPCP). Through this partnership, the National Center has advanced systems change and new initiatives at the community, state, and national levels to support family-centered medical home implementation for all children and youth, particularly those who are vulnerable and medically underserved. The NCMHI and HTPCP have collaborated closely in the following ways:

- Identifying and promoting innovative and promising practices related to medical home and family-centered care
- Sharing resources related to family-centered pediatric medical home with HTPCP grantees
- Providing technical assistance and training to HTPCP grantees
- Featuring grantees and highlighting their work in NCMHI bimonthly e-Newsletters
- Providing representation from HTPCP on the Medical Home Implementation Project Advisory Committee

About the National Center for Medical Home Implementation

The American Academy of Pediatrics (AAP or Academy) has proudly served as the “home” for the National Center for Medical Home Implementation (NCMHI or National Center), a cooperative agreement between the Academy and the Maternal and Child Health Bureau (MCHB) for the past fifteen years. The National Center is located in the Academy’s Division of Children with Special Needs in the Department of Child Health and Wellness.
In support of its mission, the National Center has developed and led numerous programs, initiatives, and resources to “move the needle” in the implementation and advancement of family-centered medical home, in addition to supporting efforts for improved health and well-being of children at the practice, community, state, and national levels.

“Nationally, the medical home concept began to evolve from a centralized medical record to a method of providing primary care from a community level, recognizing the importance of addressing the needs of the total child and family in relationship to health, education, family support, and the social environment. The concept assumed a bottom-up or grassroots approach rather than a top-down approach and shifted towards prevention, wellness, and early intervention. This concept initiated an approach toward developing a single-tiered system of care, especially for children with special health care needs.”

– Calvin CJ Sia, MD, FAAP

Between 2013 and 2018:

More than 8,500 individuals participated in NCMHI education offerings

More than 2,800 individuals were provided with NCMHI technical assistance

Participants in NCMHI educational offerings represent a diversity of NCMHI key stakeholders, including the following:

- 43% Health Care Provider/Professional
- 12% State MCH/Child Health Agency Staff
- 12% Community Organization/Staff
- 9% Family Member or Advocate
- 9% Education Provider/Professional
- 16% Other

NCMHI successfully reached a diverse target audience and increased participation from key stakeholder groups, through its activities during the grant period:

Participation by family members/advocates more than tripled

Participation by state MCH/child health agency staff more than doubled

Six times more education provider/professionals participated in education offering between 2014 to 2017
The NCMHI implemented several educational initiatives. The National Center utilized webinar technology for many of these initiatives to connect with live audiences; the recordings of the webinars were then broadly promoted and disseminated after the live event was completed.

- Webinar Series
  - **2014:** Fostering Partnership and Teamwork in the Pediatric Medical Home
  - **2015:** Care Coordination: Beyond Policy, Practice, and Implementation
  - **2016:** Thinking Outside the Box—How to Advance Health Equity and Care Quality in the Pediatric Medical Home
  - **2017:** Back to Basics—Meaningfully and Effectively Engaging Families in Pediatric Practices and Systems
  - **2018:** Where the Rubber Meets the Road—Conversations about Innovative and Promising Practices in Pediatric Medical Home Implementation

- Supporting Title V and Medicaid Collaboration in Pediatric Medical Home Implementation Webinar and Fact Sheet
- Rolling Up Our Sleeves—How to Plan and Implement QI Activities Focused on Family Engagement Webinar
- Measure What Matters—Advancing Multidisciplinary Care Coordination in Primary and Subspecialty Care Settings Webinar Series
- School-Nurse Pediatric Care Coordination Curriculum
- Leadership Education and Neurodevelopmental and Related Disabilities Medical Home Core Curriculum Module
- Healthy Tomorrows Partnership for Children Talk It Up Tuesday—Peer-to-Peer Learning Sessions
- Healthy Tomorrows Partnership for Children Return on Investment Project
- Healthy Tomorrows Partnership for Children: Sustaining Community-Based Innovations Infographic
- Presentations at Association of Maternal and Child Health Programs, Institute for Patient and Family Centered Care, CityMatCH conferences

As part of the cooperative agreement, the National Center for Medical Home Implementation (NCMHI or National Center) produced numerous tools, resources, educational materials, updates on state level medical home implementation activities, and other documents highlighting strategies and successful examples of the provision of care via the family-centered medical home model. Though the following list is not inclusive, it does provide a snapshot of the significant accomplishments achieved by the National Center.

For hyperlinked versions of the resources listed below, please see Tools and Resources.
Activities focused on the implementation and/or advancement of the family-centered pediatric medical home at the state-level and policy initiatives have been priorities of the National Center. Much of the work in policy and state-level activities done through the NCMHI occurred through a formal partnership with the National Academy for State Health Policy. Highlights from this collaboration include development of the following:

- Medical Home Initiatives and Resources by State Map
- Medicaid and Children’s Health Insurance Program State Profiles
- States At-a-Glance Table
- Medicaid Managed Care: Challenges and Opportunities for Pediatric Medical Home Implementation and Children and Youth with Special Health Care Needs
- Title V Assessment and Evaluation Project
- Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems—Care Coordination Policy Statement
- How Three AAP Chapters and Title V are Improving the Lives of Children with Special Needs Article

Development and dissemination of practical implementation tools and resources constitute the “bread and butter” of the National Center. The NCMHI tools and resources are developed with a focus on practicality and provision of important information in a succinct manner; they are publicly available for all stakeholders interested in implementing and advancing the pediatric medical home model of care.

- Building Your Medical Home Online Resource Guide
- Comprehensive, user-friendly Web site
- Salud Para Todos: Improving Health through Medical Homes
- Promising Practices Initiatives

The NCMHI panel of experts review submissions, identifies those that meet the most rigorous standards of evidence, and summarizes the implementation and outcomes of the selected projects for the Promising Practices Archive.

To date, 20 projects have been selected by the NCMHI panel to highlight to the NCMHI audience. These findings have been distributed to thousands of pediatric medical home stakeholders including pediatricians, policymakers, state administrators, community agency staff, and other stakeholders to assist with planning and implementing medical home in their states and communities.

- Innovative and Promising Practices in Pediatric Medical Home Summary Report
- Where the Rubber Meets the Road—Conversations about Innovative and Promising Practices in Pediatric Medical Home Implementation e-Learning Series
- Shared Plan of Care: A Tool to Support Children and Youth with Special Health Care Needs and Their Families Fact Sheet
- Family Engagement Quality Improvement Implementation Guide
- Enhancing Family Engagement through Quality Improvement: Lessons Learned from the Family Engagement Quality Improvement fact sheet
Family engagement is at its best in a relationship where parents and pediatric clinicians plan and deliver support together, recognizing both are necessary in order to improve the health and lives of children. Though parents are the ultimate decision makers for their own child, pediatric clinicians also bring much needed assets to the table—experience, expertise, passion, dedication and caring.”

—Janet DesGeorges, Executive Director, Hands and Voices

**NCMHI Top 10 Tools and Resources**

*Most Frequently Downloaded*

<table>
<thead>
<tr>
<th>RANK</th>
<th>TOOL/RESOURCE</th>
<th>NUMBER OF DOWNLOADS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Shared Plan of Care</td>
<td>2,192</td>
</tr>
<tr>
<td>2</td>
<td>Medicaid Managed Care Fact Sheet</td>
<td>1,615</td>
</tr>
<tr>
<td>3</td>
<td>Medical Home Care Notebook Care</td>
<td>899</td>
</tr>
<tr>
<td>4</td>
<td>Medical Home Infograph</td>
<td>782</td>
</tr>
<tr>
<td>5</td>
<td>Enhancing Family Engagement through Quality Improvement</td>
<td>484</td>
</tr>
<tr>
<td>6</td>
<td>Parents: Your Child’s Medical Home: What You Need to Know</td>
<td>434</td>
</tr>
<tr>
<td>7</td>
<td>State at a Glance Table</td>
<td>326</td>
</tr>
<tr>
<td>8</td>
<td>Webinar Series Presentation Slides: Family Engagement</td>
<td>253</td>
</tr>
<tr>
<td>9</td>
<td>ACA: Concurrent Care for Children</td>
<td>212</td>
</tr>
<tr>
<td>10</td>
<td>Medical Home Care Coordination Measurement Tool</td>
<td>196</td>
</tr>
</tbody>
</table>
Housed in the Integrated Care Program within Boston Children’s Hospital, the National Center for Care Coordination Technical Assistance (NCCCTA) has been a committed partner of the NCMHI. The mission of the NCCCTA is to support the promotion, implementation, and evaluation of care coordination activities and measures in child health across the United States. Through this partnership, the NCCCTA responded to over 200 care coordination technical assistance requests and developed numerous resources. Significant accomplishments of the NCMHI/NCCCTA partnership include:

- Environmental assessment of care coordination activities among American Academy of Pediatric chapters, Maternal and Child Health Title V / Children and Youth with Special Health Care Needs programs, and D70 State Implementation grantees
- 2017 Care Coordination Measurement Tool
- 2017 Care Coordination Implementation and Adaptation Guide
- Care Coordination Web page
- NCMHI annual webinar series on care coordination
- Measure What Matters—Advancing Multidisciplinary Care Coordination in Primary and Subspecialty Care Settings Webinar Series
- 2018 Pediatric Care Coordination Curriculum

The National Academy for State Health Policy (NASHP) has been an important NCMHI partner. As a nonpartisan forum of policymakers throughout state governments, NASHP leads and implements innovative solutions to health policy challenges. Through its partnership with the National Center, resources developed focused on Medicaid, state-based, family-centered pediatric medical home activities, and children and youth with special health care needs. Key resources developed include the following:

- Shared Plan of Care: A Tool to Support Children and Youth with Special Health Care Needs and Their Families Fact Sheet
- Medicaid Managed Care: Challenges and Opportunities for Pediatric Medical Home Implementation and Children and Youth with Special Health Care Needs Fact Sheet
The NCMHI collaborated closely with the Association of Maternal and Child Health Programs (AMCHP) on numerous activities and initiatives. As a national resource, partner, and advocate for state public health leaders and others, AMCHP works to improve the health of women, children, youth and families, including those with special health care needs. A main focus of the partnership between AMCHP and the National Center has been providing resources to states focused on National Performance Measure (NPM) 11 (medical home) to further advance the patient/family-centered care in states.

The National Center and AMCHP have collaborated closely on several initiatives / projects, as follows:

- "How 3 AAP Chapters and Title V are Improving the Lives of Children with Special Needs" article in AAP News
- Putting Evidence into Practice: Advancing National Performance Measure 11 in States article in Pulse
- Standards for Systems of Care for Children and Youth with Special Health Care Needs—provided feedback and insights as related to NPM 11
- National Performance Measure 11: Medical Home—Resources for State Title V Programs to Achieve National Performance Measure 11 Objectives; this webinar was presented at the AMCHP annual conference and showcased NCMHI tools and resources to support states in implementing family-centered care
- National Systems of Services for Children and Youth with Special Health Care Needs webinar; this webinar was hosted by AMCHP and provided medical home resources to states implementing NPM 11
- Systematic outreach to all MCH Title V and CYSHCN program directors outlining NCMHI tools, resources, and connections to state AAP chapters

The National Center also had opportunities to present at the AMCHP annual conference. Presentations included the following:

- Title V / Children and Youth with Special Health Care Needs Programs Assessment and Evaluation Project (2018)
- Advancing the Pediatric Medical Home in States: Connecting MCH Transformation to Medicaid and CHIP (Poster session with NASHP, 2016)
- Title V and Medicaid Managed Care: Partnerships to Improve Access to Medical Homes for CYSHCN (Poster Session with NASHP, 2016)
- Development of Skills to Support Effective Communication and Care Coordination in Family-Centered Care (NCCCTA Presentation Session, 2015)
- Pediatric Care Coordination for a More Effective Family-Centered Medical Home (Presentation with NCCCTA, 2014)

*The Maternal and Child Health (MCH) Block Grant, which funds state MCH Title V programs, instituted National Performance Measures intended to drive improved outcomes relative to one or more indicators of health status for the MCH population. National Performance Measure 11 is focused on medical home or patient/family-centered care.
Over the last two years, the NCMHI has shifted its focus to supporting medical home advancement and implementation occurring via state-based agencies and organizations. States have increasingly focused on population and public health models of care—to reduce health care costs and potentially improve quality of care, as indicated through the establishment of National Performance Measures (NPM) of the Title V Maternal and Child Health (MCH) Services Block Grant Program. To meet the needs of states, the National Center began to provide enhanced targeted support and outreach to states implementing NPM 11 (medical home).

One major initiative the National Center implemented through prioritizing the focus to state-based agencies was the Maternal and Child Health (MCH) Title V / Children and Youth with Special Health Care Needs (CYSHCN) Programs Assessment and Evaluation Project. The purpose of this initiative was to gain insights from MCH Title V / CYSHCN programs regarding how the National Center can provide optimal technical assistance and resources to states focused on NPM 11 and/or patient/family-centered care. Data were collected from MCH Title V / CYSHCN program staff via a quantitative survey and through key informant interviews. Data from this project were presented at a poster session at the 2018 AMCHP annual conference and an executive summary was developed, outlining key highlights project and possible next steps for the National Center. The key findings listed below provide a summary of insights gleaned from the quantitative survey and key informant interviews. For more information on findings found for this project, refer to Tools and Resources.

- Care coordination information and resources developed in partnership between the NCMHI and NCCCTA ranked as most useful resources by states implementing medical home or patient/family-centered care in their respective states
- States determined the need to identify funding, financing, and affordability strategies relevant to medical home and children and youth with special health care needs as the most pressing issue facing medical home implementation at the state-level

The National Center proudly engaged and collaborated with parents and families as equal partners through all initiatives undertaken during the cooperative agreement. Significant involvement of families and caregivers included the following:

- Providing expertise on NCMHI work groups
- Reviewing NCMHI tools and resources, including the NCMHI Web site and Building Your Medical Home online resource guide
- Serving as planning committee members and faculty for the annual webinar series
- Presenting at in-person educational events as part of the Family Engagement Quality Improvement Project (FEQIP)
- Participating as parent partners on core improvement teams for the FEQIP
- Providing representation and contributing to the work of the Medical Home Implementation Project Advisory Committee
The Path Forward

The standard of care is for every child and family to receive care that is accessible, continuous, comprehensive, patient/family-centered, coordinated, compassionate, and culturally effective. These are the characteristics essential to the provision of family-centered care. Through the work of the NCMHI, this model of care has not only become a reality for many children and their families, but also provides the basis for systems of care changes and enhancements occurring both nationally and in states.

As illustrated throughout this document, the NCMHI has been a leader in family-centered pediatric medical home implementation—particularly in the areas of technical assistance and education. The National Center has created numerous tools and resources to do the following:

- address implementation needs for all stakeholders
- continue to build relationships with national partners
- provide and support expertise in family-centered care
- show significant impact on the advancement of medical home for children and youth through clinicians, public health organizations, and state agencies

Despite the significant achievements outlined in this report, additional work is required to meet the NCMHI mission—to ensure all children, especially those with special health care needs, have access to a medical home. To continue the implementation and advancement of the family-centered pediatric medical home, the NCMHI has identified areas of focus for the family-centered pediatric medical home community in the coming years; these include activities related to systems of care, integrated care, population health, and meeting the needs of an increasing number of children and youth with special health care needs (CYSHCN).

“Pediatricians, both primary care and subspecialists, need to continue to move towards implementation of this model of care. This effort needs to be at the national and local level through multi-stakeholder initiatives, with a focus on team-based and family-centered care and overall support at all levels of care provision.”

~Adriana Matiz, MD, FAAP, Medical Director, Washington Heights Family Health Center

PO POPULATION HEALTH

Population health—“the health outcomes of a group of individuals, including distributions of such outcomes within the group”—not only refers to the health of a population as a whole but also distribution of health services through the population. States have enhanced their foci on population health and are encouraging same via work of MCH Title V / CYSHCN programs. To best support state agencies and organizations in this endeavor—especially those focused on National Performance Measure 11 (medical home)—organizations supporting state agencies will need to adopt a population health approach when developing tools and resources.
Systems of care are the service delivery arrangements comprised of health care providers and provider organizations, other community-based agencies, public and private payers, and the patients and families whom they are pledged to partner with and serve. These systems need to be strengthened and improved create a more broad, integrated process for meeting the needs of the child and the family. These systems need to become consistent in quality, costs, and outcomes across geographic and demographic domains.

To provide high quality and cost-efficient care to children and CYSHCN, state and community agencies need to collaborate and not remain siloed in their efforts. State and community agencies and / or organizations critical to the successful implementation of effective systems of care include, but are not limited to, the following:

- State Maternal and Child Health (MCH) Title V / CYSHCN programs
- Medicaid agencies and Medicaid managed care organizations
- American Academy of Pediatrics state chapters
- Family organizations, such as Family-to-Family Health Information Centers

Integrated care—much like many healthcare models (including the medical home model)—exists on a continuum. It can be implemented in a multitude of capacities: individual level; clinical setting; population level; and through public health organizations and initiatives. Integrated care is a provision of health care services, engaging the patient and family, across the entire care continuum. It relies on effective and sustainable care coordination and involves the efforts of all providers involved in the care of the patient.3 For health care providers—whether working in direct care and/or services in the clinic level or overseeing state-wide public and population health initiatives—to implement integrated care models.

One vital area of opportunity for integrated care—and all systems of care—is the continued development of evidence for their value in balancing costs with the quality of care patients and families receive. Though the evidence at the present paints a picture of integrated care as a cost-efficient system which provides higher quality care to the child and family, not enough research has taken place for this to be universally accepted amongst all systems involved in the care of children.

According to the 2016 National Survey of Children’s Health, approximately 14.2 million children ages 0-17 years in the United States (19.4%) have special health care needs.5 Children and youth with special health care needs require increased health care access, health promotion activities, and coordinated care—within a patient/family-centered medical home. Yet, according to the 2016 National Survey of Children’s Health, most children are not receiving coordinated, ongoing, comprehensive care within a medical home, demonstrating the need for additional technical assistance, training, and education among healthcare providers, child health professionals, state MCH Title V / CYSHCN programs, and other stakeholders.

Efforts to prioritize the provision of care for CYSHCN within a family-centered medical home need to be addressed not only through clinicians and other healthcare providers, but also through state agencies, public health organizations, and federally funded programs dedicated to the care and well-being of children.
AS OF 2018:

47 Maternal and Child Health Title V / Children and Youth with Special Health Care Needs programs selected NPM 11.6 (medical home) to focus area and prioritize for their states.

NPM 11: Medical Home—47 states selected are highlighted in green
Tools and Resources

**SIGNIFICANT ACCOMPLISHMENTS**

**EDUCATION**

- Webinar Series
- School-Nurse Pediatric Care Coordination Curriculum
- Healthy Tomorrows Partnership for Children: Sustaining Community-Based Innovations Infographic

**POLICY, STATE LEVEL ACTIVITIES**

- Medical Home Initiatives and Resources by State Map
- Medicaid and Children's Health Insurance Program State Profiles
- States At-a-Glance Table
- Medicaid Managed Care: Challenges and Opportunities for Pediatric Medical Home Implementation and Children and Youth with Special Health Care Needs
- Title V Assessment and Evaluation Project
- Care Coordination Policy Statement
- How Three AAP Chapters and Title V are Improving the Lives of Children with Special Needs Article

**TOOLS AND RESOURCES**

- Building Your Medical Home Online Resource Guide
- Salud Para Todos: Improving Health through Medical Home
- Promising Practices Initiatives
- Shared Plan of Care: A Tool to Support Children and Youth with Special Health Care Needs and Their Families Fact Sheet
- Family Engagement Quality Improvement Implementation Guide
- Innovative and Promising Practices in Pediatric Medical Home Implementation Summary Report
- Affordable Care Act Fact Sheets for Families (English and Spanish available)
- 2017 Care Coordination Measurement Tool
- 2017 Care Coordination Measurement Tool Adaptation and Implementation Guide
- Healthy Tomorrows Partnership for Children Sustainability Tip Sheets
- Healthy Tomorrows Partnership for Children Diversity and Healthy Equity Resource Tip Sheets
- Language Access in Pediatric Primary Care Fact Sheet
References

1 National Academy for State Health Policy. About NASHP. 
   https://nashp.org/about-nashp/. 
   Accessed May 2018

2 Association of Maternal and Child Health Programs. 
   Mission, strategic plan, and by-laws. 
   http://www.amchp.org/AboutAMCHP/About/Pages/AMCHPMission.aspx 
   Accessed May 2018

3 Boston Children’s Hospital. Pediatric integrated care survey 1.0: 
   User manual. 2015.

4 Improving Population Health. What is population health? 
   Accessed May 2018

5 Data Resource Center for Child and Adolescent Health. 
   The national survey of children’s health. 
   http://childhealthdata.org/learn/NSCH. 
   Accessed May 2018

6 Health Resources and Services Administration Maternal and Child Health. 
   National performance measure distribution. 
   https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NPMDistribution 
   Accessed June 2018

“Health equity, no matter where you’re born should allow that child to have continuity, comprehensive, compassionate care. That’s what I started and that was my dream.”

–Calvin CJ Sia, MD, FAAP