Medical Home and Equity for Children and Youth with Special Health Care Needs in Title V/CYSHCN Programs: An Overview

Introduction
The Maternal and Child Health (MCH) Services Block Grant (Title V) is the only federal program focused on the health and welfare of all mothers and children. Title V funds programs and services for 59 US states and jurisdictions. States and jurisdictions submit an annual block grant application, and a 5-year needs assessment to identify gaps and needs for their respective MCH populations. Based on the needs assessment, states must prioritize a minimum of 5 National Performance Measures (NPMs) across each population health domain. NPM 11 (medical home) is one of the 15 NPMs available for Title V programs to choose for provision of care for all mothers and children, including children and youth with special health care needs (CYSHCN). In 2020, 39 states and jurisdictions chose NPM 11 to support care for all children and CYSHCN. Nineteen states and jurisdictions prioritized equity activities in the 2020 block grant applications, highlighting access to care and care coordination as 2 critical components in “moving the needle” for more equitable care for CYSHCN.

Background and Purpose
The National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH) is funded through a cooperative agreement between the Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP). The goal of the NRC-PFCMH is to improve the health and well-being of, and strengthen the system of services for, children and youth with special health care needs (CYSHCN) and their families by providing technical assistance and supporting implementation of the patient/family-centered medical home model. The NRC-PFCMH provides technical assistance, training, and education to its main populations of interest (i.e., Title V staff, pediatricians, families of CYSHCN, and other public health partners).

The purpose of this overview is to share the process that the NRC-PFCMH conducted to guide its work related to medical home and health equity for CYSHCN. The overview notes key themes on medical home and equity from the Title V 2020 Needs Assessment and 2020 Block Grant Applications. It also presents the results of a data analysis of the National Survey for Children’s Health (NSCH). Strategies and takeaways on how Title V programs are addressing equity for CYSHCN and increasing the number of CYSHCN receiving care through medical home are highlighted. This high-level summary may be useful for other key collaborators as they work to address health equity among CYSHCN.

The NRC-PFCMH is committed to increasing equitable care for CYSHCN through the lens of medical home. Additional resources related to equity are available on the NRC-PFCMH website.

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Method
NRC-PFCMH staff reviewed 3 main data sources: the NSCH, the 2020 Title V Needs Assessment, and the 2020 Block Grant Applications to inform its activities regarding medical home and equity for CYSHN.

The state needs assessment reports and block grant applications were obtained from the Title V Information System (TVIS) website. In examining each state block grant application, NRC-PFCMH staff conducted a key word search of the following: medical home, NPM 11, care coordination, access to care and health equity. Additionally, NRC-PFCMH staff accessed and analyzed key data from the NSCH (2019-2020 combined) to compare care for children based on race and special health care needs.

Key Data from the National Survey for Children’s Health
Table 1 below highlights key data examining differences in health and access to a medical home, family-centered care, and a well-functioning system for children who identify as Black, Hispanic, or White. Table 2 shows the differences between CYSHCN and non-CYSHCN for the same variables.

<table>
<thead>
<tr>
<th>NSCH Topic</th>
<th>Black, non-Hispanic</th>
<th>Hispanic</th>
<th>White, non-Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall children’s health status – ratings for fair or poor</td>
<td>3%</td>
<td>1.9%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Percentage of CYSHCN</td>
<td>23.3%</td>
<td>16.8%</td>
<td>20.2%</td>
</tr>
<tr>
<td>CYSHCN whose care does not meet medical home criteria</td>
<td>61.3%</td>
<td>65.5%</td>
<td>44.3%</td>
</tr>
<tr>
<td>Children who did not receive family-centered care</td>
<td>17.9%</td>
<td>21.8%</td>
<td>9.9%</td>
</tr>
<tr>
<td>Children who do not receive care in a well-functioning system</td>
<td>85%</td>
<td>87.3%</td>
<td>78.3%</td>
</tr>
</tbody>
</table>

The NSCH data shows that despite having a higher percentage of CYSHCN, compared with their white counterparts, families of children who are Black or Hispanic report their children generally fared worse when it came to overall health, receiving family-centered care, care within a medical home, and care within a well-functioning system.
The table below displays the data comparing CYSHCN and non-CYSHCN children across various health-related topics. The data highlights a higher prevalence of health issues and care accessibility challenges among CYSHCN compared to their non-CYSHCN counterparts.

<table>
<thead>
<tr>
<th>NSCH Topic</th>
<th>CYSHCN (%)</th>
<th>Non-CYSHCN (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall children’s health status – ratings for fair or poor</td>
<td>7.6%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Care does not meet medical home criteria</td>
<td>57.8%</td>
<td>52.1%</td>
</tr>
<tr>
<td>Did not receive family-centered care</td>
<td>16.9%</td>
<td>13.5%</td>
</tr>
<tr>
<td>Did not receive care in a well-functioning system</td>
<td>85.6%</td>
<td>81.1%</td>
</tr>
</tbody>
</table>

Similarly, the data reveals that compared to their non-CYSHCN counterparts, families of CYSHCN report their children as having poorer health, less likely to receive family-centered care within a medical home, and less likely to receive care within a well-functioning system.

Key Data from 2020 Needs Assessment and Block Grant Applications

As noted above, 39 states and jurisdictions chose NPM 11 as one of the 15 required NPMs for the 2020 block grant application. Information on the states and jurisdictions that have chosen NPM 11 is available on the MCHB Title V Information System.

Approximately half of the states reported that their equity efforts were focused on CYSHCN and highlighted access to care and care coordination as critical components. The section below highlights key takeaways on NPM 11 and health equity for CYSHCN from the 2020 Needs Assessment and 2020 Block Grant Applications. Key takeaways and themes were identified based on reoccurring and frequently mentioned priority needs, activities, and initiatives among states. In looking at each state application, NRC-PFCMH staff used a key word search and compiled objectives, strategies, health equity projects/initiatives, and technical assistance (TA) opportunities.
### Summary of State and Health Equity Activities

#### State Strategies
- Several Title V programs utilize a health equity framework in their needs assessment planning and implementation.
- Incorporation of strategies in Title V state action plans that address health equity and social determinants of health.
- Several Title V programs noted that states are incorporating a health equity lens/approach in their outreach materials/communication to families experiencing barriers to care and with less resources.
- States are convening committees to work on health equity efforts which include diverse parent, caregiver, and youth representatives on the advisory committees.
- Various states mentioned the importance of incorporating aspects of health equity into their policies and programs that have a direct impact on maternal and child health populations.

#### Health Equity Strategies
- Title V programs continue to foster community partnerships to strengthen collaborations and provide information/resources for community-based organizations to incorporate health equity into their infrastructure.
- Efforts to address health disparities include the integration of professional development training (e.g., online modules, live webinars, and group discussions) to build internal capacities and competencies of staff to achieve health equity. States are concentrating on topics related to disparity reduction, social determinants of health, race, equity, and health literacy.
- To further assess equity efforts, states are adopting health equity indicators as measures.
- Development of a data analysis plan to assess the distribution of Title V resources and services through a health equity lens.

### Conclusion

In reviewing the 2020 Title V needs assessment, 2020 block grant applications, and 2019-2020 NSCH data, the NRC-PFCMH has opportunities to address equitable care for CYSHCN through technical assistance, training, and education for its key populations of interest (Title V, pediatricians, families of CYSHCN). Technical assistance (TA) efforts will focus on broad promotion of resources related to equity and family-centered care through the NRC-PFCMH, the AAP, and external partner organizations' networks. Additionally, the NRC-PFCMH will prioritize individual TA for state programs who are focused on National Performance Measure 11 (medical home) and/or equity for CYSHCN as written in their annual block grant application. Training and education efforts will reinforce the importance of meaningful family engagement, increase communication skills for pediatricians and allied health professionals when providing care to CYSHCN and their families, and provide strategies and promising practices for implementing an equitable, family-centered medical home for CYSHCN and their families.
Technical Assistance Resources

Visit the National Resource Center for Patient/Family-Centered Medical Home to request technical assistance to address and improve equitable, family-centered care through medical home for CYSHCN in your state or program.

For information on evidence-based/evidence-informed strategies to address NPM 11 in your state or program, please visit the Strengthen the Evidence for MCH Programs initiative.

For resources to address and improve equity in your state or program, please visit the National Center for Cultural Competence.

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