



Medical Home: Family-Centered Care is a component of [Medical Home](#) (a Universal Measure), one of twenty Maternal and Child Health (MCH) **National Performance Measures (NPMs)** for the Title V MCH Services Block Grant to States Program. This NPM subcomponent is focused on increasing the percent of children with and without special health care needs, ages 0 through 17, who have family-centered care.

For [Family-Centered Care](#), there are 12 evidence-based strategies from [MCHbest](#) and 11 field-based practices from [Innovation Hub](#). Strategies for this NPM subcomponent start on p. 3.

The [What Works Evidence Accelerators](#) provide background information and a summary of effective strategies to advance each of the NPM topic areas. The strategies support a family’s perception that doctors or other health care providers spend enough time with the child; listen carefully to the child’s caregivers; show sensitivity to the family’s values and customs; provide specific information needed concerning the child’s health and development; and help the family feel like a partner in their child’s care.¹

Overview. The Institute for Patient and Family Centered Care defines patient- and **family-centered care (FCC)** as an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.² FCC is working “with” children, youth, and families, rather than just doing “to” or “for” them.² In FCC, families define their “family” and determine how they will participate in care and decision-making.² Studies show that both children and youth with and without special health care needs benefit from FCC.^{2,3,4}

The Health Resources and Services Administration’s Maternal and Child Health Bureau (HRSA MCHB) further delineates the principles of FCC, including the following: families and professionals working together; respect for the skills and expertise brought to the relationship, trust, and open and objective communication; joint decision making; and a willingness to negotiate.⁴ Core concepts that should exist between families and professionals is dignity and respect, information sharing, participation, and collaboration.^{2,4}

FCC is viewed as a primary component of the pediatric medical home. Across all FCC models, the consistent goal is to develop and implement care plans in partnership with families.⁵ To accomplish this overarching goal, FCC models require collaboration between family members and providers, consideration of family contexts, education for patients, families, and providers, and dedicated policies and procedures.⁵ Research shows that FCC leads to better health outcomes, wiser allocation of resources, and greater satisfaction.²

Interventions and policies that support family partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—can improve health and health care.^{6,7} According to family leaders, successful family partnerships during the health care experience require the following:

- **Empower.** Try to neutralize inherent power dynamics.
- **Implement.** Practice partnership and shared decision-making.
- **Communicate.** Take time to ask what is most important to the child and family and really listen.
- **Support Family Leadership.** Meaningfully collaborate with and develop ways for families to assess and advise on FCC.
- **Connect.** Recognize the importance of high-quality, community-based services and create new pathways to missing resources.⁸

Data. This NPM is measured through data collected from the [National Survey of Children’s Health \(NSCH\)](#). In 2022, 84% of children received FCC as reported by their parent or caregiver;⁹ 81.2% of children and youth with special health care needs ([CYSHCN](#)) received FCC while 84.9% of non-CYSHCN received FCC.¹⁰ For the components of FCC, 60% of parents or caregivers reported that the child’s providers *always* spent enough time with the child;¹¹ 70.4% thought that the child’s providers *always* listened carefully to them;¹² 72.3% reported that the child’s providers *always* showed sensitivity to family values and customs;¹³ 72.2% thought that the child’s providers *always* provided information specific to parents’ concerns;¹⁴ and 72.5% felt that the child’s providers *always* helped them feel like a partner in the care.¹⁵

Social Determinants of Health (SDOH).

Family partnerships are essential in addressing the [SDOH](#) that directly impact the health, mental health, and well-being of families and communities.¹⁶ Parents are most likely to report lack of partnerships with providers if their children have functional limitations, are from racial or ethnic minority backgrounds, have low incomes, do not have health insurance, and have limited English language skills.¹⁶ The systemic issues leading to lack of partnership are the result of persistent racism, classism, and ableism.¹⁷ The consequences for families without perceived partnerships with providers are poorer outcomes (more missed school days, harder to obtain referrals for services, and unmet child and family needs)¹⁸ and less satisfaction with care.¹⁹ FCC offers an important opportunity to promote population health through systematically addressing SDOH.²⁰

Health Equity. Unequal access to high-quality primary care amplifies pervasive economic, mental health, and social health disparities.²¹ [Health equity](#) must be explicitly integrated into the core of a culture that truly engages children, youth, and families in care. Achieving this goal will require an examination of policies perpetuating systemic racism and a cultural shift to honor diversity and relationships by:

- Supporting better integration of diverse patient and family advisory councils to bring the voices of families experiencing inequity into the development of solutions.
- Implementing initiatives around health literacy to enable organizations to learn how to address and align health information and services with the knowledge, skills, and needs of families.
- Diversifying the workforce and integrating culturally responsive training approaches that recognize implicit biases and the need for cultural humility in the delivery of care.
- Increasing access to care with new models of outreach and extension of health care provision into communities through technologies such as video conferencing and telehealth.²²

CYSHCN. FCC is widely acknowledged as supporting positive outcomes in CYSHCN and their parents.²³ The American Academy of Pediatrics (AAP) regards FCC as an integral component of the medical home, and

HRSA MCHB regards FCC as a core objective for care of CYSHCN within Title V programs and Healthy People 2030 objectives.²⁴

Key Resources. The literature highlights the need for a move to FCC to improve the health and well-being of those with illness and/or disability and their families.⁵ FCC models are most commonly available for pediatric populations with a universal goal of developing care plans within the family context.⁵

The [Institute for Patient- and Family-Centered Care](#) has industry standards for FCC and should be considered a primary source for information. [Family Voices](#) has resources to support the value of family and person-centered care.

Search the [Established Evidence database](#) for peer-reviewed research articles related to strategies for increasing FCC.

Find [field-based resources](#) focused on increasing FCC relevant to Title V programs in the [MCH Digital Library](#).

Partnership and the Role of Title V. Title V programs are uniquely situated to support FCC and strengthen and advance family partnerships by:

Building Capacity:

- Training health care providers in FCC principles and practices.²⁵
- Providing formal and informal support for children, youth, and families, such as peer support, to advocate for their FCC needs.²⁴

Engaging Families and Communities:

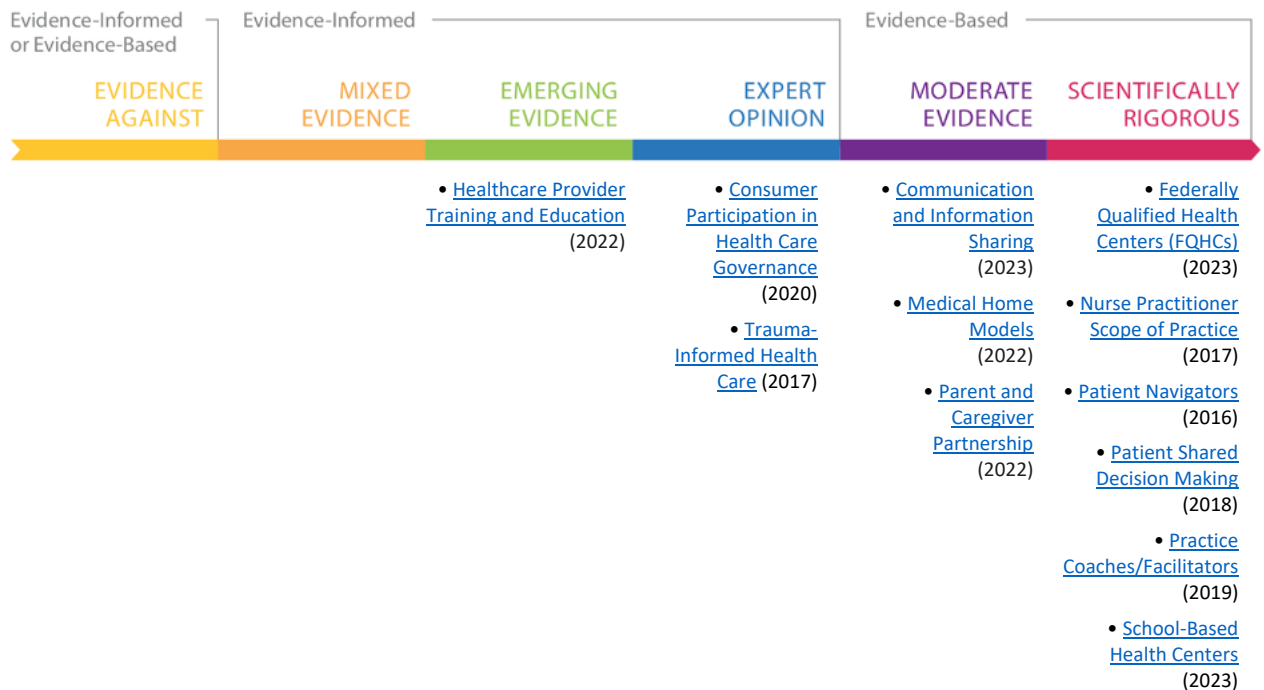
- Assuring families are key partners in health care decision-making at all levels.⁷
- Partnering with families and organizations in needs assessments, program planning, service delivery, and monitoring.⁷
- Developing referral networks to community resources.²⁴
- Utilizing culturally sensitive outreach strategies to ensure diverse communities are aware of and have access to FCC resources and support.²⁴

Promoting System and Policy Change:

- Supporting FCC-friendly policies, such as family presence, information sharing, and shared decision-making.²⁵
- Expanding measurement and evaluation systems.⁵

Family-Centered Care Strategies. This page summarizes the latest strategies and practices that have emerged as potential approaches for increasing the percent of children with and without special health care needs, ages 0 through 17, who have family-centered care. It provides a framework to identify, understand, and implement “what works” in creating new or strengthening current Evidence-based/informed Strategy Measures (ESMs). Use the links below to access strategy and practice details, approaches, supporting evidence, outcomes, and examples of how Title V agencies are either using these strategies directly or adopting components of the intervention that address this NPM.

Evidence-Based/Informed Strategies. 12 strategies have emerged from studies in the scientific literature as being effective in advancing the NPM. They can be adopted or adapted to meet your program needs. More information on these strategies can be found in the MCH Evidence Center’s [MCHbest](#) database.



Field-Based Practices. 11 practices from state-/community-based programs have emerged as potential approaches for advancing the NPM for specific communities or populations. They can be used as models to meet your program needs. More information can be found in the Association of Maternal and Child Health Program’s (AMCHP’s) [Innovation Hub](#).



Key Findings for Family-Centered Care. The following are key findings emerging from the literature:

1. Key components of effective programs that advance FCC include cultural sensitivity,²⁶ structured communication (including language translation), understanding and validating parents' experiences, shared decision-making, and providing support and resources.²⁷
2. Parent participation programs, family-integrated care models, and the use of new technologies (as part of a digital health environment) such as bedside boards can improve communication, engagement, attachment, and health outcomes in neonatal care settings.²⁷
3. Multimodal approaches to communication skills training, including deliberate practice and patient feedback, can be effective in improving FCC experiences.²⁸
4. Parents expressed the need for emotional support, education, connection with peers, and assistance in navigating the healthcare system. They emphasized the importance of parent-infant bonding, education on caregiving, and connecting with other parents and families.²⁷
5. Provider training stressed the importance of family members as partners in care, the establishment of common ground with peers, honest communication, consistent messaging, and an emotional connection with all involved in care.²⁹

Discussion: Research, Practice, Partnership.

Research. Multiple strategies are emerging as potential approaches to advance this NPM, but they have not been studied with enough rigor to be included in the evidence-based continuum. Additional research is needed to verify outcomes, but initial studies have shown promise of these strategies in MCH settings:

- Supporting family navigators to provide direct contact related to advocacy, care coordination, community resources, and emotional support.³⁰
- Establishing patient and family advisory councils to provide experience that can help enhance service delivery and improve overall quality.³¹
- Promoting health literacy to assist families in participating in the care of their children.³²

- Incorporating family feedback and satisfaction surveys into care and interactions.³³
- Supporting parent-to-parent networks for families to connect and share experiences.³⁴
- Integrating FCC content into telehealth visits to facilitate two-way communication.³⁵

Practice. The following tools can be used to translate evidence to action to advance this NPM:

- [Family-Centered Care Assessment Tool](#) (Family Voices). The assessment measures a caregiver's perception of FCC received by their child.
- [Patient- and FCC Organizational Self-Assessment Tool](#) (NICHQ). This tool assesses how an organization is performing in relation to specific components of patient- and FCC.

Partnership. The following organizations focus efforts on advancing FCC:

- [AAP Medical Home Resources](#). Outlines FCC components and provides an extensive [FCC Resource Portal](#).
- [Family Engagement and Leadership in Systems of Care](#). Supports and develops the network of F2Fs.
- [Institute for Patient- and FCC Care](#). Provides training, educational programs, and best practices.



Frameworks and Tools for “What Works.”

Use this accelerator to strengthen current or new programs that align with multiple MCH frameworks across domains and settings. Access toolkits related to these frameworks for additional resources:

- [MCH Evidence Framework](#)
- [Blueprint for Change for CYSHCN](#)
- [Maternal Health Toolkit](#)
- [Life Course and Social Determinants Brief](#)

Need More Help? [Contact us for training and technical assistance](#) customized to your needs.

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References

- ¹ Retrieved from [2022 NSCH-1 English \(census.gov\)](https://www.census.gov)
- ² Retrieved from [Institute for Patient and Family-Centered Care \(ipfcc.org\)](https://www.ipfcc.org)
- ³ Kuo DZ, Frick KD, Minkovitz CS. Association of family-centered care with improved anticipatory guidance delivery and reduced unmet needs in child health care. *Matern Child Health J.* 2011 Nov;15(8):1228-37.
- ⁴ Kuhlthau KA, Bloom S, Van Cleave J, Knapp AA, Romm D, Klatka K, Homer CJ, Newacheck PW, Perrin JM. Evidence for family-centered care for children with special health care needs: a systematic review. *Acad Pediatr.* 2011 Mar-Apr;11(2):136-43.
- ⁵ Kokorelias KM, Gignac MAM, Naglie G, Cameron JI. Towards a universal model of family centered care: a scoping review. *BMC Health Serv Res.* 2019 Aug 13;19(1):564.
- ⁶ Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, Sweeney J. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood).* 2013 Feb;32(2):223-31.
- ⁷ U.S. Department of Health and Human Services, Health Resources Administration, Maternal and Child Health Bureau, Division of State and Community Health. Title V Maternal and Child Health Services Block Grant to State Program: Guidance and Forms for the Title V Application/Annual Report. Retrieved from [Title V MCH Services Block Grant Guidance and Reporting Forms 10th Edition December 2023 \(hrsa.gov\)](https://www.hrsa.gov)
- ⁸ Retrieved from [Family-Professional Partnerships in Pediatric Health Care \(aap.org\)](https://www.aap.org)
- ⁹ Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/10/2024] from www.childhealthdata.org. [NSCH 2022: Medical Home Component: Family-centered care, Nationwide \(nschdata.org\)](https://www.childhealthdata.org)
- ¹⁰ Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/10/2024] from www.childhealthdata.org. [NSCH 2022: Medical Home Component: Family-centered care, Nationwide, Special health care needs status \(nschdata.org\)](https://www.childhealthdata.org)
- ¹¹ Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/10/2024] from www.childhealthdata.org. [NSCH 2022: Doctors spent enough time with the child, Nationwide \(nschdata.org\)](https://www.childhealthdata.org)
- ¹² Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/10/2024] from www.childhealthdata.org. [NSCH 2021 22: Doctors listened carefully, Nationwide \(nschdata.org\)](https://www.childhealthdata.org)
- ¹³ Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/10/2024] from www.childhealthdata.org. [NSCH 2022: Doctors showed sensitivity to family's values and customs, Nationwide \(nschdata.org\)](https://www.childhealthdata.org)
- ¹⁴ Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/10/2024] from www.childhealthdata.org. [NSCH 2022: Doctors provided specific information for parental concerns, Nationwide \(nschdata.org\)](https://www.childhealthdata.org)
- ¹⁵ Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/10/2024] from www.childhealthdata.org. [NSCH 2022: Doctors helped parents feel like partners in child's care, Nationwide \(nschdata.org\)](https://www.childhealthdata.org)
- ¹⁶ Deatrick JA. Where Is “Family” in the Social Determinants of Health? Implications for Family Nursing Practice, Research, Education, and Policy. *Journal of Family Nursing.* 2017;23(4):423-433.
- ¹⁷ Rosenfeld, L., & Litt, J. S. (2023). To achieve equitable, integrated care for children, family-centered work must focus on systems. *Families, systems & health: the journal of collaborative family healthcare*, 41(4), 547–549.
- ¹⁸ Kenney MK, Denboba D, Strickland B, Newacheck PW. Assessing family-provider partnerships and satisfaction with care among US children with special health care needs. *Acad Pediatr.* 2011 Mar-Apr;11(2):144-51.
- ¹⁹ Smalley LP, Kenney MK, Denboba D, Strickland B. Family perceptions of shared decision-making with health care providers: results of the National Survey of Children With Special Health Care Needs, 2009-2010. *Matern Child Health J.* 2014 Aug;18(6):1316-27.

- ²⁰ Garg, A., Jack, B., & Zuckerman, B. (2013). Addressing the social determinants of health within the patient-centered medical home: lessons from pediatrics. *JAMA*, 309(19), 2001–2002.
- ²¹ Robinson SK, Meisner M, et al., eds. *Implementing High-Quality Primary Care: Rebuilding the Foundation of Health Care*. Washington DC: National Academies Press; 2021 May 4.
- ²² Simon M, Baur C, Guastello S, Ramiah K, Tuft J, Wisdom K, Johnston-Fleece M, Cupito A, Anise A. Patient and Family Engaged Care: An Essential Element of Health Equity. *NAM Perspect*. 2020 Jul 13;2020.
- ²³ Geri M, Lotze, Melissa H. Bellin & Donald P. Oswald (2010) Family-Centered Care for Children With Special Health Care Needs: Are We Moving Forward? *Journal of Family Social Work*, 13:2, 100-113.
- ²⁴ Kuo DZ, Houtrow AJ, Arango P, Kuhlthau KA, Simmons JM, Neff JM. Family-centered care: current applications and future directions in pediatric health care. *Matern Child Health J*. 2012 Feb;16(2):297-305.
- ²⁵ Seniwati T, Rustina Y, et al. Patient and family-centered care for children: A concept analysis. *Belitung Nurs J*. 2023 Feb 12;9(1):17-24.
- ²⁶ Koch M, Grier K. Communication and Cultural Sensitivity for Families and Children with Life Limiting Diseases. *J Hospice & Palliative Nursing*. 22(4)270-275.
- ²⁷ Lemmon ME, Glass HC, et al. Family-Centered Care for Children and Families Impacted by Neonatal Seizures: Advice From Parents. *Pediatr Neurol*. 2021 Nov;124:26-32.
- ²⁸ Marsh M, Lauden SM, et al. Family-centered communication: A pilot educational intervention using deliberate practice and patient feedback. *Patient Educ Couns*. 2021 May;104(5):1200-1205.
- ²⁹ Doherty RF, Knab M, Cahn PS. Getting on the same page: an interprofessional common reading program as foundation for patient-centered care. *J Interprof Care*. 2018 Jul;32(4):444-451.
- ³⁰ Godoy L, Hodgkinson S, et al. Increasing Mental Health Engagement From Primary Care: The Potential Role of Family Navigation. *Pediatrics* April 2019; 143 (4): e20182418.
- ³¹ Retrieved from [Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices \(nichq.org\)](https://nichq.org)
- ³² Clay AM, Parsh B. Patient- and Family-Centered Care: It's Not Just for Pediatrics Anymore. *AMA J Ethics*. 2016;18(1):40-44.
- ³³ Hummel K, Presson AP, Millar MM, Larsen G, Kadish H, Olson LM. An Assessment of Clinical and System Drivers of Family Satisfaction in the PICU. *Pediatr Crit Care Med*. 2020 Oct;21(10):e888-e897.
- ³⁴ McCrossin J, Lach L. Parent-to-parent support for childhood neurodisability: A qualitative analysis and proposed model of peer support and family resilience. *Child Care Health Dev*. 2023 May;49(3):544-554.
- ³⁵ Brody AA, Sadarangani T, et al. Family- and Person-Centered Interdisciplinary Telehealth: Policy and Practice Implications Following Onset of the COVID-19 Pandemic. *J Gerontol Nurs*. 2020 Sep 1;46(9):9-13.

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