Moving Beyond the Family Engagement Check Box: An Innovative Partnership to Promote Authentic Family Engagement in Systems Change
About CSSP
The Center for the Study of Social Policy works to achieve a racially, economically, and socially just society in which all children and families thrive. We do this by advocating with and for children, youth, and families marginalized by public policies and institutional practices. For more information, visit http://www.CSSP.org.

About Family Voices
Family Voices, a national, family-led, non-profit organization, works to improve health care services and supports for children through effective partnerships with families and family-led organizations. Staff and network members, who are themselves families of children with special health care needs and disabilities (CYSHCN), bring the voices of families representing the cultural, linguistic, ethnic, and geographic diversity of the nation to influence decisions at all levels of health care. For more information, visit https://familyvoices.org/.
Acknowledgements

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Suggested Citation

Moving Beyond the Family Engagement Checkbox: An Innovative Partnership to Promote Authentic Family Engagement in Systems Change Executive Summary

This case study examines the partnership that the Center for the Study of Social Policy (CSSP) and Family Voices undertook to create and implement a process for engaging families in the Pediatrics Supporting Parents (PSP) national initiative to promote the social and emotional development (SED) of young children. While many individuals and organizations, including funders, see the value of family engagement, they often struggle with the logistics of how to engage families. This case study provides valuable insights about best practices for engaging families, describes a framework for implementing family engagement in systems-level initiatives and why it is important, and highlights the significance of providing adequate funding for family-led organizations and for individual family leader participants.

Importance of partnership with a family-led organization

Collaborations with family-led organizations, such as Family Voices, are an effective way to build the capacity of policymaking organizations, state agencies, and other systems of care to support meaningful family engagement that can ensure that policies, practices, and services are family-centered and equitable. Family-led organizations, with their broad networks of families, have direct connections to families who represent the racial, ethnic, cultural, linguistic, and geographic diversity of their community, state, and the nation. Family-led organizations can recruit, mentor, support, and provide skill-building leadership opportunities to family members who specifically represent the diversity of the population served to participate in initiatives to transform systems of care.

CSSP and Family Voices identified three opportunities where family leaders could impact the PSP initiative to transform the delivery of pediatric well-child visits to promote the SED of young children.

1. Establishing and working with an advisory group of diverse parents of young children, formally called the “Brain Trust.”

2. Including family leaders, along with pediatricians and CSSP staff, as members of Site Visit teams to observe best practices for promoting SED.

3. Inviting family leaders from the Brain Trust and Site Visit teams to participate and present at an in-person Convening Meeting of stakeholders.
Promoting Meaningfully Engaging Families

Based on a qualitative analysis of a comprehensive literature review and a series of key informant interviews with family leaders and professional partners to learn about barriers to family engagement and to identify key criteria that support meaningful family engagement in systems-level initiatives, Family Voices created a Framework for Assessing Family Engagement in Systems Change. The framework is organized into four domains of family engagement: Commitment, Transparency, Representation, and Impact that each include items that promote, enhance, and sustain family engagement in systems-level initiatives. CSSP and Family Voices staff identified criteria in each domain that would support meaningful family engagement in all three activities.

For example, the Commitment Domain addresses the importance of compensating family leaders for sharing their expertise and time. CSSP worked with funders to include a budget for Family Voices staff and the family leaders. Compensation is also an equity issue, as without reimbursement, families may not be able to take time from other work to participate and cover additional costs, such as transportation or childcare, associated with family engagement activities.

The Transparency Domain addresses the information and supports an organization provides to both staff and families to ensure they can participate and contribute. Family Voices mentored the family leaders so they felt prepared for meetings and confident in their advisory roles, particularly around addressing issues of cultural humility and race equity.

The Representation Domain underscores the importance of engaging families who are representative of the population served by the initiative. CSSP created a job description for the Brain Trust noting the preference for parents who are diverse, and who had a child younger than 10.

Families are often asked to provide feedback, but organizations rarely follow up about if and how they used the information. The Impact Domain identifies the importance of telling families how the information they shared was used. CSSP staff acknowledged the family leaders’ contributions in their reports, noting how it expanded their perspective on the barriers families experience and how programs could, or could not, support families, foster community, and address culture and racism.

Call to Action: Changing the Paradigm for Family Engagement

Funders may intuitively understand that including families’ perspectives is important. However, if they develop the strategic plan, budget, and methodologies before engaging families, it creates or maintains barriers in the systems that the funder is attempting to change. The PSP initiative demonstrates how engaging families early on, in all aspects of a project, is critical to the outcome. Funders should require family engagement as a best practice to reduce barriers to care and ensure systems changes that benefit all families.
Recommendations to Ensure Meaningful Family Engagement in Systems-Level Initiatives

• Partner with family-led organizations from the start of an initiative to recruit and mentor family leaders, with a focus on family leaders who are representative of the target population to be served by the initiative.

• Provide and create opportunities for family leaders to participate as equal partners on steering committees or design teams to help develop the design, strategic plan, budget, and implementation and evaluation of the project.

• Invest in the infrastructure of family-led organizations so that families are prepared and available to participate as effective partners in policymaking and on other decision-making groups. The federal government invests in family-led organizations at the state and national level to support families to become effective health, education, and mental health advocates both for their own children and as partners with professionals in systems improvement. Private foundations have an important role to play in leveraging these federal investments to bolster and expand this infrastructure of family leaders.

Funding family-led organizations to develop robust approaches and to recruit and mentor family leaders to engage in health care system transformation can yield a huge return on investment. Grant funding for family engagement is often an afterthought and the funding is insufficient for families to engage in the full scope of work necessary to transform how health care services are delivered. There is substantive family leadership in the country that can help funders change these paradigms. Changes in how projects are funded, the composition of project partners, and how the project is implemented are essential to achieve the country’s shared goals of equitable, effective health care and improved social and emotional development of young children.
Part I: Introduction

This issue brief examines the partnership that the Center for the Study of Social Policy (CSSP) and Family Voices undertook to create and implement a process for engaging families in the Pediatrics Supporting Parents (PSP) national initiative to promote the social and emotional development of young children. The PSP Steering Committee, CSSP staff, pediatricians, other stakeholders, and the family leaders engaged in the PSP Initiative recognized the impact that families had on the project. While many individuals and organizations, including funders, see the value of family engagement, they often struggle with the logistics of how to engage families. This case study provides valuable insight about best practices for engaging families, describes a framework for implementing family engagement in systems-level initiatives and why it is important, and highlights the significance of providing adequate funding for family-led organizations and for individual family leader participants. It also includes a Call to Action and Recommendations to Ensure Meaningful Family Engagement in Systems-level Initiatives. Family Engagement is particularly critical as communities grapple with the impacts of the coronavirus pandemic, which is disproportionately affecting families of color and with low income. Ensuring that families are part of the identification of problems and solutions that the pandemic has and will uncover will yield invaluable benefits for improving future systems and services.

Increasingly, state Title V and Medicaid agencies, hospitals, and other child- and family-serving health care entities recognize that family engagement in systems-level initiatives, where policy decisions are made, is integral to creating and supporting a well-functioning system of care. As public health, healthcare, and early childhood systems work to reduce health disparities, developing meaningful partnerships with the parents and families who receive these services is a key strategy for promoting family-centered care and equitable outcomes for all children and families. Families who receive services have important perspectives on the quality of services and achievement of family-centered outcomes. They can provide valuable insights into the challenges they face, share how specific solutions can improve or exacerbate access to services, and help identify solutions that can improve the design and implementation of services.

While many organizations understand the benefit that families’ lived experiences can bring to their program and policy initiatives and strive to promote equity, many do not know how to engage families in their work. They have difficulty recruiting representative families to participate in such work. When families are invited to participate, both professionals and family leaders are frequently uncertain about their roles in such a

* A family leader is a family member with lived experience who can participate in systems-level activities around policies and programs that affect the broader population of individuals who receive services.
partnership and participating families often do not have the information and support they need to contribute in meaningful ways. This brief provides recommendations, supported by concrete examples from the PSP Initiative, about how organizations and foundations can begin or strengthen family engagement work, leading to more equitable programs, initiatives, and systems.

**Importance of partnership with a family-led organization**

There is a growing body of evidence that family engagement in systems-level health care initiatives improves patient safety and health outcomes, reduces system fragmentation and barriers to care, and improves health policies.\(^1\,\,^2\,\,^3\,\,^4\) Collaborations with family-led organizations are an effective way to build the capacity of policymaking organizations, state agencies, and other systems of care to support meaningful family engagement that can ensure that policies, practices, and services are family-centered and equitable.

Although state agencies, national foundations, and other family-serving organizations may have the best of intentions to identify policies and practices that could be improved to increase families’ access to care and to other needed services and supports, they often lack a direct connection to the families who could help them in these improvement efforts. They lack efficient ways of identifying, preparing and supporting families to participate in improvement activities.\(^6\,\,^7\) Family-led organizations, with their broad local, state, and national networks of families, have direct connections to families who represent the racial, ethnic, cultural, language, and geographic diversity of their community, state, and the nation. Family organizations can recruit, mentor, and support family members who specifically represent the diversity of the population served to participate in systems transformation initiatives. Family organization staff who are experienced family leaders can mentor families who are engaging in systems-level initiatives for the first time. Mentors share their knowledge and experience to help less experienced family leaders understand how to use their personal experiences to provide input that will improve the system of care for all children and families.\(^6\) Such mentoring and support help families relate their own experiences to the need for policy change.

In addition to mentoring newer family leaders, staff from family-led organizations can provide skill-building leadership opportunities to both family leaders and professional staff. Leadership training on family engagement develops a shared understanding of authentic engagement, helps families and professionals coalesce around issues, ensures relevant participation, and prepares them to work effectively together. Joint learning opportunities, where family leaders and professional staff learn about group process, and have opportunities to identify their individual perceptions of problems help prepare all participants to listen and learn from each other and work together in a respectful manner to transform and improve a system of care.

Recognizing the challenges and opportunities around meaningful family engagement at the systems level,” the PSP Steering Committee asked CSSP to collaborate with Family Voices to provide the information, support, and mentorship families might need to participate in and contribute to the PSP initiative.

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\(^*\) Family Voices defines systems-level family engagement as authentic partnerships between professionals and family leaders who reflect the diversity of the communities they represent, working together at the systems level to develop and implement better policies and practice.
PART II. CASE STUDY: ENSURING MEANINGFUL FAMILY ENGAGEMENT IN THE PEDIATRICS SUPPORTING PARENTS INITIATIVE

This section provides an overview of the Pediatrics Supporting Parents Initiative, three key activity areas where family leaders were engaged, and the Family Voices Framework for Assessing Family Engagement in Systems Change that guided the work.

Overview of the Pediatrics Supporting Parents Initiative

Research shows that children’s social and emotional development (SED) is vital for school readiness and is a key building block for cognitive development and learning at very young ages [8]. It also underscores that a healthy parent-child relationship is a primary driver of healthy social and emotional development [8]. In navigating the joys, uncertainties, and challenges of raising a child, parents often seek support and guidance from their family, friends, and trusted professionals, such as primary care providers. Pediatric care guidelines recommend that infants and young children have twelve well-child visits up to age three. With over 90 percent of all young children receiving at least one well-child visit in 2018,9 pediatric well-child visits present a unique opportunity for supporting parents in nurturing their children’s social and emotional development and relational health.

In 2017, several leading national foundations, recognizing this opportunity within pediatrics, formed a steering committee and launched Pediatrics Supporting Parents (PSP), a national initiative that focuses on nurturing the parent-child relationship and recognizes that the parents’ mental health is a critical mediator. The PSP Steering Committee partnered with CSSP to identify and study evidence-based practices that innovative pediatric primary care clinics are using to promote the social and emotional development of young children. After reviewing nearly 70 programs, CSSP choose 10 programs and conducted 12 site visits (some programs had more than one site) around the country. These programs used family-centered methods to support children’s social and emotional development. The qualitative data and research from these site visits helped CSSP identify 14 common practices and the systemic barriers that prevent their widespread implementation. In Fostering Social and Emotional Health through Pediatric Primary Care: Common Threads to Transform Everyday Practice and Systems, CSSP provides recommendations for actions to advance enhanced pediatric primary care that supports parents to promote the social and emotional development of their young children.
Early in the PSP initiative, CSSP recognized that health care could alleviate, or exacerbate, disparities in children’s health and development, and that parents’ experiences with health care providers directly affects their children’s care. The PSP initiative presented an opportunity to learn how clinical sites:

- **Address race equity and implicit bias**
- **Partner with families**
- **Honor culture**
- **Attend to power differentials between families and the health care team, and**
- **Develop community partnerships to address social determinants of health (SDOH).**

CSSP recognized that in order to fully understand these equity issues and to ensure the findings and recommendations reflected the needs of diverse families, it was critical to partner with and engage parents of young children, who represent the population the PSP initiative was addressing in this work.

CSSP reached out to Family Voices for assistance. Family Voices is committed to family engagement at all levels of health care. Family Voices works to support families as partners in decision making at the individual level concerning the care of their child, as well as at the systems level where policies and practices are improved or created. Family Voices reaches families through a national network of 59 federally funded Family-to-Family Health Information Centers (F2Fs) in all 50 states, the District of Columbia, five territories, and three tribal nations. F2Fs are staffed by family members with first hand experience and knowledge about systems of care and resources. They help families understand and navigate complex systems of care, including insurance, and connect them to additional services and supports. F2Fs also collect data about the problems and barriers families experience in obtaining services for their children. Family Voices and CSSP staff worked closely together to design and implement a robust approach for engaging families in the PSP initiative.

**Family Engagement activities in PSP**

In addition to the overall planning and implementation activities, CSSP and Family Voices identified three opportunity areas to engage grassroots families in the PSP initiative.

1. **Establishing and working with a “Brain Trust” representing a diverse group of parents**

   Family Voices and CSSP recognized the primary importance of recruiting and engaging parents who had recent experience with pediatric well-child care for a young child as central advisers to the initiative. As their children’s primary caregivers, families are deeply affected by systems-level issues, such as racism and implicit bias, and primary care billing practices that do not allow sufficient time to discuss social and emotional development and address parents’ overall concerns about their children. These lived experiences make families uniquely qualified
to partner in shaping systems-level policies that can improve primary well-child care for young children. This group of families, named the “Brain Trust,” identified the central role that family perspectives would bring to the work. Family Voices recruited families who were representative of the race/ethnicity, language, culture, gender, and geographic diversity of the population being addressed by the national PSP initiative, including children with and without special health care needs. A Family Voices staff member with academic, professional, and personal experience with issues of racism and equity, as well as family leader development, mentored each of the members individually, and the Brain Trust as a group, through regular and frequent calls.

The Brain Trust met monthly with CSSP and Family Voices to help inform the design of site visits to learn more about best practices for promoting the social and emotional development of young children. They suggested rephrasing and adding questions to ask staff and families, as well as elements to observe, such as if members of the care team were representative of the population served, the languages in which signage was posted in the office, if staff smiled when greeting families, and if books in the waiting room were available in multiple languages. They reviewed and reflected on the data gathered from the site visits and helped identify strategies that addressed equity, leveled power differentials, and encouraged trusting relationships between families and providers. The Brain Trust also helped plan and develop the agenda for an in-person convening of pediatric site teams, family leaders, and national experts, and participated in the development of recommendations for a final report.

2. Conducting Site Visits

CSSP visited twelve pediatric sites that were implementing programs that promote the social and emotional well-being of young children. Each site visit team included two CSSP staff, a pediatrician, and a family leader from the local community or state. Four site visits occurred in close proximity to Brain Trust members’ residences, and in those instances, Brain Trust members joined the site visit teams. In the remaining eight sites, Family Voices recruited local family leaders to participate on the site visit team. The family leader was an integral member of each site visit team, providing a family perspective about the physical facility and interactions with staff. They collected data about the strategies necessary to promote a child’s social and emotional well-being and the parent-child relationship, asking questions to providers and families in order to understand the lived experience of families at each pediatric site. They also participated in a post-visit debriefing session and were invited to share their experience during Brain Trust meetings.
3. Participating in an In-person Convening Meeting

CSSP organized a one-day meeting of all the PSP initiative partners to review study findings, contribute to the final recommendations, and develop ideas for dissemination. The meeting included national stakeholders, representatives from the program sites, pediatricians, and family leaders who participated in the site visits, three members of the Brain Trust, and CSSP and Family Voices staff.

Just being at the table where I was not the only “Family Leader” was huge! Many organizations say that they value families and their opinions; however, I had never really seen this many parents having a seat at the table, in one setting, as equal partners.

— Family Leader

Meaningfully Engaging Families in All Aspects of a Health Care Transformation Initiative

In 2018, Family Voices developed a Framework for Assessing Family Engagement in Systems. The framework is organized into four domains and includes key criteria that promote, enhance, and sustain family engagement in systems-level initiatives, such as the PSP initiative. CSSP and Family Voices staff identified key criteria in each domain that would be necessary to recruit and support family leaders engaged on the Brain Trust, on site visit teams, and as participants at the in-person convening meeting.
The key criteria in this domain identify the extent to which an organization demonstrates a commitment to engaging family leaders in policy and programs that govern the services received by children, youth, and families.

**Have a Family Engagement Policy & Champion**

CSSP, an equity-driven organization, served as the champion for engaging families throughout this initiative. Its *Manifesto for Race Equity & Parent Leadership in Early Childhood Systems* acknowledges that parents have unique expertise that must be included in all phases of health care system transformation. It also recognizes that conscious and unconscious bias and structural racism prevent parents from being true partners in systems change. CSSP staff recognized that it was critical to engage in its design the families that the PSP initiative intended to serve. Knowing that they had no direct contact with these families, they recognized the importance of collaborating with a family-led organization, such as Family Voices, to not only identify and recruit diverse family leaders to participate, but also to ensure that the families had the supports they needed to participate and contribute to their maximum potential.

**Provide Funding**

The importance of fairly compensating family participants is critical to the success of family engagement. Family leaders need to be paid for sharing their time and expertise in recognition of the value of their input. Compensation is also an equity issue, as without adequate payment, families may not be able to take time from other work to participate and cover additional costs, such as transportation or childcare associated with family engagement activities.

CSSP worked with the PSP Steering Committee to ensure that the budget included funding to sustain the partnership with Family Voices staff throughout the initiative. The budget included funding for CSSP and Family Voices staff to meet weekly to discuss progress, upcoming tasks, logistics, and any concerns about the family engagement work. This bi-directional communication was essential in developing a strong, trusting partnership between the two organizations. The budget also
included funding to support Family Voices staff time to recruit and mentor the members of the Brain Trust and the family leaders on the site visit teams. It also included funding to compensate staff at Family Voices Affiliate Organizations and/or Family-to-Family Health Information Centers in each state who helped recruit families for the Brain Trust and site visit teams. Family leaders who participated in the Brain Trust, the site visits, and the one-day convening in Washington, DC received stipends for each aspect of their work.

**Acknowledge Families’ Contributions**

Acknowledging family contributions promotes a culture of engagement and encourages leaders whose commitment is recognized to continue to strengthen these partnership activities. As part of needs assessments and research projects, organizations often ask for family input on surveys, at focus groups, and on advisory committees. Unfortunately, staff rarely follow up with families to let them know what has changed based on their input. The CSSP report, *Fostering Social and Emotional Health through Pediatric Primary Care: Common Threads to Transform Everyday Practice and Systems*, documents the significant contributions the Brain Trust made to the PSP initiative and describes the changes made to the site visit protocol based on suggestions from the Brain Trust. CSSP also acknowledged the Brain Trust’s contributions to the themes they identified based on review and discussion of the qualitative data collected during the site visits. In addition to the regular mentoring feedback that Family Voices provided to the Brain Trust and site visit family leaders to facilitate their participation, the CSSP team gave feedback to the Brain Trust and the site visit family leaders through regular meetings and debriefs throughout the project. These structures ensured effective “closing of the loop” in terms of feedback to families, which the family leaders greatly appreciated.

*My experience with the Pediatrics Supporting Parents initiative was unique and encouraging! I'm often asked to participate in community and state level “think tanks” to bring a parent perspective to the group. I typically share my story...provide feedback/constructive criticism...only to see the group move forward with little change. From day one of my involvement in this initiative, CSSP and Family Voices made it very clear that parent input was important and necessary for this project to succeed.*

— Family Leader
Domain 2: Transparency

Two-way transparency builds trust and ensures that all participants have the same information. Key criteria in this domain address the information and supports an organization provides to both staff and families to ensure they can participate and contribute.

Provide Mentorship

The mentorship process prepared the family leaders to elevate the importance of their family voice in every aspect of the work, and to demonstrate the value of meaningful and effective family engagement, particularly around issues of cultural humility and race equity. Several of the family leaders on the Brain Trust had experience participating in state level projects, but none had worked at the national level. The relationship with a Family Voices mentor provided an ongoing opportunity for them to express their concerns, build skills and confidence, and be prepared to engage in each stage of this national initiative to transform pediatric well-child care.

Throughout the PSP initiative, a Family Voices staff member with a deep understanding of racism and cultural issues mentored all the family leaders who participated. The mentor established a trusted, supportive relationship with each family leader participant, helping to orient each family leader to the work. The mentor helped families prepare for meetings by discussing meeting materials in advance, asking and answering questions, and thinking through ideas—much like the opportunities professional colleagues have to talk together before meetings. The family leaders lived in different states, across three time zones. Having a mentor to speak with provided an opportunity to exchange ideas prior to each Brain Trust and site visit meeting.
The Family Voices mentor also convened prep calls for the Brain Trust families prior to monthly Brain Trust calls with CSSP. The calls helped establish group cohesion, provided additional opportunities for each family leader to think through the materials in advance of the Brain Trust call, exchange thoughts and ideas, and share their perspectives based on their diverse experiences with their own children. The mentor also arranged individual calls with each family leader to discuss their role at the meeting, hear what the family leader hoped to contribute to the meeting, and what they hoped to learn. These individual calls provided emotional support and helped build the family leaders’ confidence.

In addition, the Family Voices mentor worked individually to prepare each family leader who participated in the site visits. This included providing each site visit family leader with an orientation to the PSP project, the purpose of the site visits, the family leader’s role, and a review of the site visit protocol and questions for the care team and families at the site. In addition, the mentor participated on the full team prep calls for each of the site visits to ensure family leaders were introduced to the other members of the site visit team and understood all the logistics.

I appreciated the coaching and check-ins from Family Voices [mentor] to encourage positive participation and understanding of the work to be done. I was impressed with the genuine interest the pediatricians and other stakeholders had in what our parent leaders offered.

— Family Leader

The impact of this mentorship was demonstrated when family leaders from the Brain Trust presented at an opening plenary panel at the CSSP PSP National Convening meeting in Washington, DC near the end of the initiative. This was a new experience for the three Brain Trust families who participated. The mentor worked with the family leaders to develop the questions they would respond to and how they would convey their intended message. In preparation for the panel, family leaders shared their responses with the mentor, who provided feedback on content and timing. As a final step in their preparation, the mentor conducted a group conference call to prepare the family leaders for the panel and to increase their comfort with the format. The family leaders spoke compellingly from their perspective as women and mothers of color about cultural humility, race equity, and their experiences accessing health care for their children.
Explain the Work & Provide Clear Expectations

Job descriptions send an important message to families, namely, that family members have a defined and important role, rather than being invited to simply fulfill an expectation or requirement to have a family present.

Before beginning the recruiting process, CSSP and Family Voices created job descriptions for roles on the Brain Trust and Site Visit teams. This included a brief write up of the background and scope of the PSP initiative, duties and responsibilities. The descriptions specified experience and skills needed, such as having a child under 10 years old, interest in promoting social and emotional well-being and the parent-child relationship for young children, and capacity and interest in representing underserved groups such as children of color, immigrants, and families of limited income.

Hold Meetings at Everyone’s Convenience and Provide Materials in Advance

Family Voices and CSSP polled the Brain Trust members to identify a consistent day and time for meetings that fit families’ work and home schedules and maximized their participation. Meeting agendas and materials were jargon free and sent in advance of the preparatory and Brain Trust meetings.
Individuals and families who receive services from a system of care are uniquely qualified to help drive system transformation because they understand the barriers to access and quality of services. Key to being representative is that the families who engage in systems-level partnership must represent the race, ethnicity, language, gender, geography and any other important characteristic of the target population receiving services from a system.

**Recruit Diverse Families Through Family-led Organizations**

Representative family leaders understand the barriers that families like them face in accessing services. They can identify solutions that not only meet their families’ needs, but can also inform systems-level changes to improve access and quality for all families. CSSP understood the necessity of engaging family members for the Brain Trust who were representative of the race, ethnicity, language, gender, and geography of the PSP target population.

Family Voices shared the Brain Trust job description, which focused on recruiting diverse parents who had a child younger than 10, with its national network of family-led organizations. The response was quick and enthusiastic, yielding 13 potential candidates. Family Voices had individual calls with each, and based on race, ethnicity, language, gender, and geography, CSSP and Family Voices offered the Brain Trust opportunity to five family leaders, all of whom accepted. The Brain Trust included four mothers and one father. Two were African American and one was White. The other two members were immigrants. All had children younger than 10, some with special health care needs, some without. They lived in Connecticut, New Jersey, Indiana, Kansas, and California, providing perspectives from rural, urban and suburban communities.
Domain 4: Impact

Impact describes the areas in which an organization integrates family leaders’ ideas to improve policies and programs.

Use Family Leaders’ Input to Improve the Initiative

The strong relationships built between the family leaders, Family Voices, and CSSP were fundamental to the project’s success. Among the most powerful aspects of this influence was the clarity of the voices of the diverse Brain Trust family leaders sharing their perspectives on health equity and culture during a panel presentation at the National Convening meeting, and in their participation in the written report describing the findings from the work.

During site visits, the family leaders on each team brought their personal experiences, perspectives, and stories about what it was like raising young children and receiving services in pediatric primary care. They were often from the local community or a neighboring community and were able to reflect on the programs and services in the context of the communities’ needs and culture. Their familiarity with the community enabled them to connect and relate to the parents enrolled in local programs, creating an environment where local parents who were interviewed as part of the site visit felt more comfortable sharing their experiences. Moreover, family leaders shared their stories with the site visit staff, sometimes bringing a new point of view on what was valuable about the program, or what could be improved. For example, a site visit family leader who was a foster parent to a young child noted that a specific service offered by the program site would have helped her build the parent-child relationship with her son and helped strengthen his relationship with his birth mother.

A physician doesn’t necessarily need to “look” like you in order to build a connection and relationship. But they do need to see you as a person, recognize your culture, understand your unique struggles, and find somewhere you can relate to each other on a personal level as parents and people. Providers need to address their own biases to bridge gaps and build relationships.

— Family Leader
As CSSP was developing a list of common practices observed during the site visits that could universally enhance the parent experience in primary care, staff discussed the findings with the Brain Trust and a consulting group of pediatricians. While the Brain Trust and pediatricians had some similar priorities, there were also differences. The family leaders and the pediatricians both identified community partnerships with clear processes and protocols as a priority. However, while the Brain Trust prioritized outreach to parents prenatally to build relationships and the importance of creating opportunities for families to connect with other families, the pediatricians focused on what they could control within the context of well visits.

The pediatricians prioritized the enhancement of anticipatory guidance with videos and materials focused on social and emotional development and the parent-child relationship, and standardization of workflow by designating roles among the care team. While writing the final report, the CSSP team decided to include a wide range of practices in order to emphasize the diversity of perspectives and needs, which included the Brain Trust’s selection of prenatal outreach.

In developing the project recommendations, family leaders honed in on the role families should play in system change and scaling. They conveyed why it is critical to listen to the perspectives of families when implementing change and new services; how proposed changes will impact scale and quality; and how changes will need to be adapted for the unique context of given populations or settings. In each case, the parent voice is fundamental in the planning discussions—one size will not fit all. Throughout this process, family leaders posed questions and shared reflections with CSSP and other local and national partners. The family leaders’ input expanded CSSP’s perspective on what parents and families really want and need, the barriers they experience and how programs could, or could not, support their families, foster community, address needs, and be attentive to culture and racism.

Without the parent leaders, we would have written a different report—one that left out critical opportunities to expand the way pediatrics can support the social and emotional development of young children.

— CSSP Project Director
The diverse and rich family engagement in the PSP initiative has strongly influenced how the steering committee and other PSP partners consider equity, culture, relationships, and overall family engagement in their work. The opening panel of three family leaders from the Brain Trust along with the presence of nine additional family leaders who went on site visits set the tone for the one-day in-person convening at the conclusion of the work. During the panel, and less formally throughout the day, all 12 family leaders shared their personal experiences with primary care providers. A prevalent theme was the problematic frequency with which primary care teams disregard parents’ concerns about their children’s development. Parents understand and respect pediatricians’ medical expertise, but pediatricians often fail to recognize that parents know their children best. They forget the importance of a trusting doctor-patient-family relationship and working together to address children’s social and emotional development. These personal stories, takeaways from site visits, and recommendations for addressing cultural differences and implicit bias to promote social and emotional well-being in children created a sense of urgency for moving the PSP work forward. One family leader reflected:

Being a part of this project and attending last week’s convening meeting was exciting, amazing, encouraging, and insightful for what is to come in the future. Having the opportunity to share my professional knowledge and personal story with parent leaders validates the necessity for parents to have a seat at the table alongside service providers and medical professionals when decisions are being made that can affect the lives of young children. I am so proud and honored to be a part of this project and especially the Brain Trust. This is absolutely a step in the right direction for change in the way we advocate, care for, and make medical decisions for young children and the families who support them.

— Family Leader
PART III. CALL TO ACTION: CHANGING THE PARADIGM FOR FAMILY ENGAGEMENT

As of 2018, children younger than 5 years made up 6.1% of the U.S. population,\textsuperscript{10} and the U.S Department of Education reported that 6 out of 10 are not prepared for kindergarten.\textsuperscript{11} Foundations understand that investing in the development of programs and policies that transform systems can improve the lives of young children and their families. These types of system transformations are especially important to address systemic barriers to obtaining the supports all families require to ensure the health and social and emotional well-being of their children, which is an important part of kindergarten readiness. Focused changes are especially critical to better serve those families living at or below the poverty level, those who experience the impacts of racial inequality, those who live in resource poor areas without ready access to health care services, and those without available community supports.

Funders may intuitively understand that including the perspectives of these families is important. However, if they wait until the strategic plan, budget, and methodologies for the work are already developed before engaging families, it creates or maintains barriers in the systems that the funder is attempting to change. The PSP initiative demonstrates how engaging families early on, in robust ways, in all aspects of a project, is critical to the outcome. Funders should consider engaging families from the ground up as a best practice in order to reduce the barriers to family engagement and truly invest in transformative systems change.

The investment in family engagement will be particularly critical as the nation and communities address the impact of the coronavirus crisis, which is disproportionately affecting people of color. Available grant funds will be strained at a time of crisis. A comparatively small investment in engaging the voices of families in initiatives to address this crisis and its aftermath can yield high returns. Families can help us address the disproportionate impacts of the crisis on diverse and low-income communities, and the implications for all health transformation efforts. Families’ experiences in the current crisis can better prepare us to address future challenges.
Recommendations to Ensure Meaningful Family Engagement in Systems-level Initiatives

- Partner with family-led organizations from the start of an initiative to recruit and mentor family leaders, with a focus on family leaders who are representative of the target population to be served by the initiative.

- Provide and create opportunities for family leaders to participate as equal partners on steering committees or design teams to help develop the design, strategic plan, budget, implementation and evaluation of the project opportunity.

- Invest in the infrastructure of family-led organizations so that families are prepared and available to participate as effective partners in policymaking and on other decision-making groups. The federal government invests in family-led organizations at the state and national level to support families to become effective health, education, and mental health advocates both for their own children and as partners with professionals in systems improvement. Private foundations have an important role to play in leveraging these federal investments to bolster and expand this infrastructure of family leaders.

Funding family-led organizations to develop robust approaches and to recruit and mentor family leaders to engage in healthcare system transformation can yield a huge return on investment. **Grant funding for family engagement is still too often an afterthought with the funding insufficient for families to engage in the full scope of work necessary to transform how health care services are delivered. There is substantive family leadership in the country that can help funders change these paradigms.** Changes in how projects are funded, the composition of project partners, and how the project is implemented are essential to achieve the country’s shared goals of equitable, effective health care and improved social and emotional development of young children.
### Appendix: Family Leader Acknowledgements

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<th><strong>Family Voices Brain Trust</strong></th>
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<td>Ashley Bates-Crowley</td>
<td>Family Leader, Executive Director/Co-Founder, Team Josiah 2K22 Foundation</td>
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<td>Erica Walker</td>
<td>Family Leader</td>
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<tr>
<td>Kasey Dudley</td>
<td>Family Leader, Autism Medical Home Program Coordinator/Parent Leader, SPAN</td>
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<td>Norman Ospina</td>
<td>Family Leader, Interpreter &amp; Translator, SumaPinta Language Justice Services</td>
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<td>Yohana Ramirez</td>
<td>Family Leader</td>
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<th><strong>Family Voices Site Visit Family Leaders</strong></th>
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<tr>
<td>Alisa Bentley</td>
<td>Quality through Technology and Innovation in Pediatrics (QTIP)</td>
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<td>Gabriela Chavarria</td>
<td>Promoting First Relationships and Reach Out and Read</td>
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<tr>
<td>Jennifer Balzanelli</td>
<td>Massachusetts Project LAUNCH (Linking Actions for Unmet Needs in Children’s Health)</td>
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<td>Jill Sirko</td>
<td>Family Connects</td>
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<td>Jody Brigham</td>
<td>Healthy Steps Show Low</td>
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<td>Paola Lozano</td>
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<td>Tila Mims</td>
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<td>Yetta Myrick</td>
<td>Mental health Outreach for MotherS (MOMS) Partnership</td>
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Sources


