PEDIATRICS Supporting PARENTS

CLINICAL PRACTICE

FAMILY PARTNERSHIP

GOVERNANCE

Strengthening Family Partnership:

Insights From Pediatrics Supporting Parents

HOW TO READ THIS SERIES OF THREE WHITE PAPERS

This paper focuses on Pediatrics Supporting Parents' approach to family partnership; companion papers examine clinical practice and governance.

Each paper can be read on its own with no specific starting point.

These papers are grounded in what the initiative as a whole and the Proof Point Communities experienced, tried, and learned during implementation.

Reflection prompts are included to support discussion, adaptation, and use in other settings.

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Methodology Overview: *This paper explores how Proof Point Communities shifted from a traditional participation model of family engagement toward collaborative family partnership. It highlights the guiding values behind this work, the structures that have supported it at both the local and initiative-wide levels, and the ways these efforts are influencing care delivery, cross-site learning, and family experience. This paper presents a qualitative synthesis grounded in interviews, site experiences, and recurring themes observed across PSP communities.*

Introduction

The pediatric well-child visit is one of the few recurring points of contact that families have with the health care system during the earliest years of a child's life. Throughout the first three years alone, families attend up to 12 well-child visits, creating repeated opportunities to support children's health, well-being, and the relationships and caregiving environments that contribute to their early development.

Pediatrics Supporting Parents (PSP) emerged from a growing recognition, reflected in research from the Center on the Developing Child (2016) and the American Academy of Pediatrics (Garner et al., 2012), that the quality of *early relational health*—the state of the relationships surrounding young children, especially in the earliest years—plays a foundational role in long-term social, emotional, and physical well-being. PSP explored what might become possible if the work already happening in pediatric care, from vaccines and screenings to developmental checks, was approached with early relational health and family partnership in mind.

> **"The goal of Pediatrics Supporting Parents has been to reimagine what's possible in pediatric care—especially in the well-child visit."**
>
> – MARY ANN WOODRUFF, MD, FAAP, PEDIATRICIAN, PIERCE COUNTY PPC

> **"The pediatric channel is a universal access point—a way to meet families where they are."**
>
> – INDIA ALARCON, PSP PROJECT DIRECTOR & FUNDER COLLABORATIVE LIAISON, ALARCON CONSULTING

Through partnership with five competitively selected Proof Point Communities (PPCs), PSP explored how social-emotional development and early relational health could become a consistent part of everyday pediatric practice, with approaches tailored to what each community was learning from its families, systems, and local context. Within these communities, pediatricians, family leaders, administrators, and community organizations worked together to test and refine new ways of delivering care, strengthening relationships during visits and improving connections between families and supports beyond the clinic.

PSP and Family Partnership

PSP grew from the belief that family members and caregivers are essential partners in advancing pediatric care. This commitment is reflected in PSP's core values: that parents are experts on their own children; that effective care is strengthened through collaboration between families and providers; that pediatric care should support the well-being of the family alongside the child; and that strong parent-child relationships are foundational to healthy development.

Guided by these values, PSP invested in family leadership as a way to deepen collaboration between families, clinicians, and community partners, with family leaders contributing their lived experience and perspectives along with clinical expertise. Research indicates that the relationship runs both ways: Family partnership builds the trust that allows providers to understand families more fully and respond more effectively (Doyle et al., 2019). This approach helps identify opportunities, set priorities, and shape approaches that reflect the strengths, needs, and cultural contexts of the communities being served.

Family partnership within PSP took shape on two interconnected levels. At the local level, family leaders worked with pediatric teams and community partners to co-create clinical workflows, communication approaches, policies, and resident training, thus helping ensure that care reflected the realities, strengths, and needs of families. At the national level, family leaders served as voting members of the PSP Governance Body, contributing lived experience to strategic direction, budget decisions, and priority setting. More details on changes in clinical practice and PSP's governance approach and structure are available in the companion white papers.

Supporting this type of participation across both settings required investment in how family leaders were recruited, prepared, and supported. PSP developed this infrastructure in partnership with Family Voices, the national family engagement partner for the initiative. Their guidance was grounded in an evidence-informed framework that emphasizes commitment, transparency, representation, and impact and that shapes how compensation, preparation, and ongoing support are structured so family leaders can meaningfully participate at all levels of the initiative. Although family partnership practices varied among PPCs, the work included evolving relationships and decision-making structures, embedding family partnership into organizational policies and culture, and funding approaches that support meaningful compensation for family leaders as subject matter experts.

Drawing on Family Voices' experience and each PPC's own definition of co-creation, a broader team collaborated to finalize this overarching PSP definition:

- Co-creation is the process of authentic partnering between professionals and those with lived experience, rooted in shared decision-making and mutual respect, to advance a shared goal or outcome.

The individual PPC definitions and the structures they used to support family partnership can be found on each PPC's landing page at the PSP microsite.

From Participation to Partnership

Many health care and early childhood systems have long engaged families in efforts to improve services and care experiences. Common approaches such as surveys, listening sessions, and advisory councils provide structured opportunities for families to share their perspectives on improvement work.

PSP expanded opportunities for family leaders to work alongside clinicians, administrators, and community partners to shape priorities, workflows, and approaches to care. This role brought family perspectives into decision-making from design through implementation.

> **"Parents are used to the routine. We're in focus groups. We do all of the things, and we're often repeating the same experiences over and over. You tell your story enough times, you start looking for what changes."**
>
> – SHAYLA COLLINS, FAMILY LEADER, PIERCE COUNTY PPC

Across PPCs, family leader participation was also shaped by practical and structural factors that influence who can engage consistently. Time constraints, transportation challenges, child care responsibilities, language access, and financial pressures can affect families' ability to participate. Additionally, although pediatric care often represents one of the most trusted points of contact for communities, some families arrive having had previous experiences with health care systems that felt dismissive, culturally misattuned, or difficult to navigate, creating additional barriers.

Within this context, PSP focused on creating conditions to support sustained family leader engagement. This included paying attention to how family leaders were recruited, prepared, and included in planning, implementation, and improvement activities alongside clinicians and other partners. Together, these efforts reflected a meaningful shift from participation toward partnership.

Table 1 provides examples of how family partnership differs from more common approaches to family participation.

Table 1. From Participation to Deeper Partnership

 Participation	 Deeper Partnership
• Family voice is gathered in response to priorities set by the organization. • Parent input is collected periodically through surveys or meetings. • Families are primarily viewed as recipients of services. • Engagement activities operate alongside core clinic or system operations. • Decisions about programs and policies are largely made within institutions.	• Family knowledge and perspectives help shape priorities from the outset. • Partnership is integrated into ongoing planning, implementation, and decision-making. • Families co-design priorities, workflows, and approaches from the outset. • Family partnership influences how care, communication, and coordination are organized. • Decision-making increasingly incorporates family perspectives, priorities, and realities.

Honoring Lived Experience: Equitable Compensation for Family Leadership

In an effort to recognize family leaders as expert consultants, PSP explored what it would look like to provide financial parity, developing a compensation model that paid family leaders a professional rate reflective of their lived experience and subject matter expertise. This section describes how PSP initially approached compensation, why it matters, what it covered, and how the rate was set, along with the practical and logistical supports that made sustained participation possible for families navigating work, caregiving, and other demands.

Recognizing and Compensating Family Expertise: Family partnership requires acknowledgment of the time, labor, and the expertise that family leaders contribute. Historically, many family engagement efforts have relied on volunteer participation or small tokens of appreciation, such as gift cards. PSP explored a new approach grounded in the premise that the contributions of family leaders—their time, preparation, and expertise—are compensated on par with other professionals at the table.

The Labor Involved: PSP set out to have family leaders contribute more than periodic feedback and, instead, to engage them in the co-creation of clinical workflows, clinic policies, and pediatric resident training, as well as decisions at the initiative's national level. Recognizing the full scope of this contribution, PSP developed a compensation approach that reflected the substantial investment of time, expertise, and intellectual labor that the work required.

Setting the Rate: Working in partnership with Family Voices, PSP developed a direct payment model and established a standard rate of $125 per hour for family leaders, a figure grounded in conversations about what would appropriately reflect their contributions as consultants with lived expertise.

> **"We were tired of the $20 gift cards. You want our time and information—that you're going to use in your research for perpetuity, and you don't want to pay? Nah. . . . I'm not recruiting anybody, if my folks ain't gonna be able to get at least a certain amount of money that they feel is sufficient for their expertise, their brilliance, wisdom, time and for sharing their story."**
>
> – SHAYLA COLLINS, FAMILY LEADER, PIERCE COUNTY PPC

In setting the rate, PSP also considered the practical realities of participation. Attending meetings, preparing materials, and engaging in governance often required family leaders to step away from work or navigate other competing responsibilities. The compensation level was intended to acknowledge those realities and reduce the barriers that might otherwise make sustained participation difficult.

> **"We wanted the parents to have parity because we value their expertise as much as from other professionals. And they are professionals."**
> – ELIZABETH KRAUSE, MEMBER OF PSP FUNDER COLLABORATIVE, PERIGEE FUND

Reducing Financial Barriers to Participation: As PSP developed its compensation approach, it also examined the limitations of reimbursement-based participation models. Although reimbursement can offset expenses, it often requires family leaders to pay costs upfront and navigate administrative processes before being repaid, an arrangement that can create real barriers for families managing tight budgets.

In response, PSP explored what it would look like to cover meeting-related costs directly and in advance. For in-person convenings, that meant arranging payment for airfare, lodging, and per-diem expenses ahead of time so family leaders would not need to assume any financial burden. Child care was also considered, with communities offering on-site support or the initiative covering travel expenses for a child and caregiver. This ensured that family leaders could participate without the added logistical or financial stress of arranging care.

> **"Getting paid has made it a lot easier for me as a parent to give my time, to be able to express myself, especially with the commitments and meetings. And it means a lot to me. It tells me that what I have to say, what I have lived—it has value. They are not just saying thank you. They are doing something about it."**
> – ZULMA GALDAMEZ, FAMILY LEADER, DURHAM COUNTY PPC

Building Capacity for Partnership

Treating lived experience as a form of expertise also raised practical questions about participation itself: How could parents and caregivers engage as full and confident partners within systems shaped by technical language, institutional norms, and long-standing professional hierarchies? PPCs found that transparency, deliberate preparation, relationship-building, and ongoing support made a difference, including something as practical as ensuring that family leaders received agendas and materials for decision-making in advance.

In preparation for Governance Body meetings, Family Voices held monthly meetings exclusively for family leaders, without the presence of funders, clinicians, or other staff, creating space for honest reflection, troubleshooting, and peer support. Formal training sessions covered topics from professionalism and mission development to résumé building and public speaking, with templates and worksheets provided after each session as concrete tools for immediate use.

Family Voices also provided technical assistance and training to PPCs on family engagement assessment practices, policies and procedures, and job descriptions for family leaders. For family leaders whose preferred language is not English, Family Voices provided translation and interpretation services and encouraged family leaders to expect and request the same in other high-level settings. The Family Voices team also helped PPCs establish the operational infrastructure needed to support family partnership, including compensation processes and invoicing systems.

> **"What made it easier for me to stay in governance and feel comfortable enough [there], was the trainings and workshops that got me prepared for what I was going to be doing."**
>
> – HEATHER BUSHNOE, FAMILY LEADER, ONONDAGA COUNTY PPC

When ZERO TO THREE joined as the backbone organization in July 2023, they restructured how family leaders were convened and supported, refining PSP's Learning Community—a cross-site network of clinicians, family leaders, funders, and local partners—and shifting from quarterly meetings to more frequent, topic-focused, and interactive Communities of Practice (CoPs). The CoPs were designed so family leaders, clinicians, and other partners could learn and contribute together. The first CoP focused on family partnership, with ZERO TO THREE contracting a family leader to cofacilitate with Family Voices and backbone staff. Teams that chose to engage were asked to include a family leader alongside at least one clinician or administrator. ZERO TO THREE staff also made themselves available to family leaders on an ongoing basis, helping them troubleshoot challenges and clarify information.

> **"They [ZERO TO THREE] made us feel like their doors were always open. You could always email them. I never had an issue when it came to communication. And if I was a little lost . . . I felt like they were always there. Kim and Sarah were amazing."**
>
> – ZULMA GALDAMEZ, FAMILY LEADER, DURHAM COUNTY PPC

As parents became more comfortable working within clinical and administrative environments, many took on more visible roles within their communities. Family leaders organized community events, connected families to resources, created parent-to-parent networks, and helped other caregivers understand opportunities to engage with local initiatives. In Onondaga County, members of the Parent Advisory Council worked with staff and launched Better Together Onondaga, an online platform created "for parents by parents" to share information and strengthen community connections. These activities reflect a broader shift in confidence and leadership as family leaders work to expand the initiative's reach.

Creating a More Collaborative Space

Equipping family leaders to participate was only one part of deepening partnership. PSP also invested in the structures and processes needed to support shared decision-making at both the national and local levels. During a 12-month planning period after the selection of the PPCs, clinicians, community representatives, family leaders, funders, and national partners worked together to develop PSP's initiative-wide governance structure, establish shared processes and practices, and create the 12-member Governance Body that would guide the work. During this same period, PPCs developed and refined local governance and family partnership approaches tailored to their communities and aligned with PSP's goal of creating structures where family leaders, clinicians, and other partners could share responsibility for shaping the work.

With the establishment of the co-created Governance Structure, the initiative developed shared expectations around roles, decision-making processes, and how the Governance Body and broader Learning Community would work together. Early sessions included activities that helped participants build relationships, develop a shared understanding of the work, and establish shared norms, bridging perspectives and roles that do not often work with one another. The Governance Body also experimented with decision-making tools, such as gradients of agreement, which allowed members to express different levels of support or concern and created space for discussion and nuance.

> **"It is one thing to say that you value lived experience as expertise . . . . but if the conversation isn't being had in a way that everyone can actually participate, it's not going to happen."**
>
> – ELLIE ERICKSON, MD, FAAP, IMH-E, PEDIATRICIAN, DURHAM PPC

Family Voices played a central role in developing accessible governance materials and helping establish a common language. They created multiple versions of key documents to reduce technical language and ensure that materials were accessible across differences in background, experience, and familiarity with institutional processes.

> **There were some things that I had to push on when it came to the language . . . I don't mean plain language, I mean like plain plain language. The people who are seen at our clinic are not attorneys, [they] are not judges . . . so we need to be able to communicate better."**
>
> – ZULMA GALDAMEZ, FAMILY LEADER, DURHAM PPC

Work at the national level helped shape shared expectations that were then reflected in local PPC governance and planning spaces. Each community received tailored one-on-one technical assistance, training, and compensation support from Family Voices. Tools such as the Family Engagement Readiness Assessment helped communities plan, assess, and strengthen family partnership over time.

Family Partnership in Action

Family partnership within PSP took shape through concrete examples of family leaders contributing to policies, priorities, and system improvements. In Pierce County, through the Learning Journeys: Family Partnership in Pediatric Care innovation, family leaders helped reframe how missed appointments were understood. They revealed how terms such as "failed appointment" can carry a judgment that does not acknowledge that families have to navigate certain hurdles, including transportation, child care, and work-related constraints. This perspective shifted attention toward understanding barriers and identifying more supportive responses to missed visits.

The Durham PPC made a parallel change, with family leaders and staff revising no-show policies and replacing a punitive missed-appointment letter with communication that begins with empathy rather than consequences.

> **"How can we identify the barriers and actually be curious about helping parents get to their appointments, as opposed to just penalizing them?"**
>
> – RACHEL LETTIERI, ADMINISTRATOR, PIERCE COUNTY PPC

In San Francisco, family leaders on the Family Accountability Board partnered with the Toxic Stress Network Improvement Collaborative (TONIC) to strengthen earlier support for families. Drawing on lived experience with Medi-Cal and child welfare systems, they highlighted gaps where services often begin only after crises escalate. Their input helped shape a pilot offering case management support before Child Protective Services re-entry, supporting earlier intervention. TONIC's work has also informed policy discussions on dyadic care and enhanced care management, now reimbursable Medi-Cal benefits that expand access for millions of families.

> **"Families did not just give feedback. We helped build solutions based on real lived experience. Bringing in families as equal partners absolutely changes the conversation, ensuring that system redesigns actually solve what families need."**
>
> – DANIEL VÁSQUEZ, FAMILY LEADER, BAY AREA PPC

Another example of family partnership in action occurred at the broader initiative-wide level through the adaptation of Facilitating Attuned Interactions (FAN). The original FAN tool and its training, created at Erikson Institute, are built on the idea that people need to feel connected and understood before they are ready to try new things. FAN is a communication and mindfulness tool that helps practitioners tune into the feelings of both parties in any interaction so they can respond with empathy and in ways that fit the situation.

This version, the Family Leaders FAN, was co-created by PSP family leaders, the Erikson Institute, and Family Voices. It is designed specifically to support family leaders who are entering systems-change work and engaging in planning, decision-making, and workflow changes—spaces many may not have navigated before.

The overarching goal is for family leaders to recognize and respond effectively to the communication cues of others while simultaneously respecting their own experience. This shift was reflected in the reframing of FAN's concept of "mindful self-regulation" into the question: *How can I be settled within myself to allow myself to respond the way I need to?* Once piloted, this new version of FAN will use a peer-to-peer training model to help family leaders feel more confident in their vital roles of supporting families in their determination to thrive, centering healing for themselves and their communities, and contributing to systems change.

Reflections and Implications

One of the key learnings from PSP's experience is that operationalizing family partnership involved intentional structures and practices that supported the sustained engagement of family leaders in the work. Throughout the initiative, communities created opportunities for family leaders to contribute alongside clinicians, administrators, and other partners in planning, decision-making, and improvement efforts.

Each PPC approached this engagement differently, but several common elements emerged. Family leaders were compensated for their expertise and received preparation, coaching, and opportunities to build confidence before engaging in decision-making spaces. Meetings were designed to be more accessible through interpretation, plain language, flexible scheduling, child care, and skilled facilitation.

The long-term sustainability of family engagement remains an important consideration, with mixed progress across cultural and financial dimensions. Culturally, PPCs and funders have taken steps to shift how institutions understand family expertise and shared decision-making, increasingly embedding family partnership into practice. Financial sustainability, however, remains an ongoing challenge, particularly in determining how to support this work beyond grant funding.

Philanthropic investment can help establish a foundation for this work, and communities can reinforce it by embedding family partnership into organizational policies and budgets. Although this approach helps reduce reliance on short-term funding cycles, sustaining compensation also requires dedicated resources that support not only stipends but also the infrastructure and staff time needed to prepare and support family leaders. Looking ahead, continued exploration of policy mechanisms to sustain these roles will be important for the field.

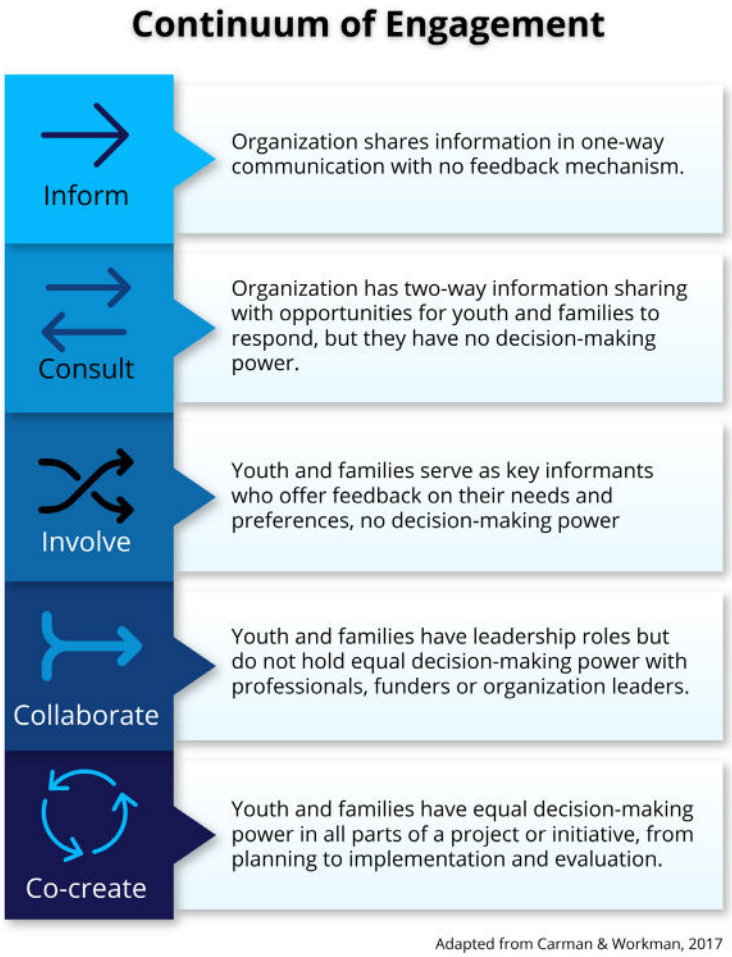
A Tool for Reflection

PSP's experience suggests that this work is less of a program to implement and more of an ongoing shift in how organizations operate. It invites reflection on readiness to engage families and on long-standing assumptions about expertise, authority, and decision-making.

Family Voices offers a discussion guide that organizations can use to explore these questions for themselves.

The path toward co-creation rarely follows a straight line, and where a community begins matters less than the progress it makes along the way.

This continuum of engagement pictured right, developed by Family Voices, is not intended as a performance measure. Communities may find themselves operating differently from one context to another; for example, engaging around deep collaboration in clinical workflow redesign while relying on more traditional budget discussions. This variation is common. A useful question is not where a community falls on a continuum but where existing patterns persist and what conditions might support different approaches.



Adapted from Carman & Workman, 2017

PSP's experience also suggests that these patterns are not fixed. Choices about compensation, preparation, facilitation, and decision-making shape what becomes possible in practice. PPCs and the national infrastructure, including the funder collaborative, Family Voices, and ZERO TO THREE, made these choices intentionally, contributing to forms of partnership that many participants had not previously experienced.

Taken together, the most transferable learning from PSP is not a specific model or structure but the recognition that family partnership depends on a set of conditions: recognizing lived experience as expertise, compensating family leaders for their contributions, preparing participants for engagement, and ensuring that family perspectives meaningfully inform decisions. When these conditions are present, family leaders contribute not only their lived experience but also their insight, perspective, and leadership, which help keep the work grounded in the realities of the families it is intended to serve.

Considerations for Family Partnership

Every PPC began somewhere, and the starting point was rarely a fully built partnership structure. More often, it began with a willingness to examine the structure that was already in place and whether it created the conditions for authentic partnership. The following questions are offered as practical entry points for any practice working to move beyond family participation toward co-creation, with insights from PPCs on how they considered these questions.

Where does family expertise currently shape decisions, and where are there opportunities to move from informing toward co-creation?

Advisory councils, surveys, and listening sessions create valuable opportunities for input, but PSP found that deeper partnership emerged when family leaders, clinicians, and other partners worked together to shape priorities, co-create workflows, and determine budget decisions.

How does your organization compensate family leaders for their time and expertise?

PSP found that compensation decisions were an opportunity to recognize family leaders as contributors with lived expertise and responsibilities comparable with those of other roles. That meant examining whether the rate and structure of compensation for family leaders reflected the full scope of their contributions, including their time, preparation, and the level of engagement.

How are family leaders being prepared and supported so they can participate with confidence?

PSP discovered that deliberate preparation made a big difference. Sharing materials in advance, providing coaching around institutional language and norms, and connecting family leaders to peer networks helped ensure that they could engage as co-creators rather than reactive respondents in environments that they did not design.

What kinds of changes can support more inclusive participation in meetings and conversations?

Slowing the pace of discussion, clarifying technical language, building in time for questions, and using tools such as small-group discussion or relationship-building activities all helped create more space for family leaders to contribute substantively.

These questions do not have a single answer, and each PPC has crafted innovations and new approaches along the way. PPCs found that the shift from participation toward deeper partnership tends to come from intentional choices about structures, supports, and how families are engaged in shaping the work. The PPCs that invested in these changes found them worthwhile. Progress lies less in following a prescribed approach and more in creating space for family leaders to contribute as partners in shaping care.

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