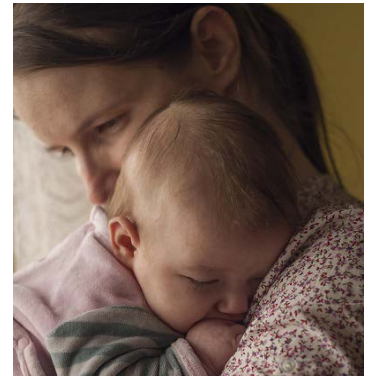


My Baby, My Doctor & Me



Hearing from Parents about Foundational Relationships and the Role of the Health Care System in promoting Early Relational Health

The Center for Improvement of Child and Family Services
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Acknowledgements

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The Center's mission is to engage in equity-driven research, evaluation, and consultation to promote social justice for children, youth, families, and communities.

Project Background

There is a growing national effort to encourage child and family health care systems¹ and providers to see the relationship between parents and caregivers and their infants as critical to the developing child's overall health, sometimes referred to as "early relational health".² In this view, these foundational early relationships are seen as substantially influencing long-term physical and emotional well-being³. However, much of the work to date has not centered or fully engaged the voices and experiences of historically marginalized families. In the fall of 2019, a small group of stakeholders in Oregon, including funders, family/child health care system staff, and researchers, brought together by Dr. David Willis, a long-time advocate for the importance of early relational health, committed to exploring ways to fill this gap.

The resulting study focused specifically on exploring parent perspectives on foundational early relationships, and the potential for the family and child health care system to play a supportive role, by working with three groups of families: (1) African American mothers living in inner Northeast Portland; (2) Spanish-speaking Latinx mothers living in rural Oregon; and (3) White mothers living in an isolated rural community in Southern Oregon. Using an explicitly exploratory approach, the project was designed to generate questions and identify areas in need of further research and learning that will be important to advancing the ongoing dialogue about family voice, equity and the concept of early relational health.

Engaging Community & Family Partners

A guiding assumption for the work was that in order to more effectively elevate parents' experiences, the team should authentically engage parents at every stage of the project, from shaping the research questions to interpreting and helping share the findings. To do this, the PSU research team contracted with three community **Research Liaisons** with strong existing relationships with the identified groups of parents. Research Liaisons then engaged and facilitated input from three teams of 3-4 **Parent Research Consultants** (PRCs). Each Research Liaison worked with one team of PRCs. PRCs were paid a \$400 honorarium in return for their participation. Over the course of the one-year project, PRCs participated in a series of up to six working sessions during which Research Liaisons facilitated their input on the research. The meetings were structured around the key phases of the project (Figure 1). PRCs also helped to identify and invite parent participants to focus

groups which were ultimately determined to be the best method for gathering data from parents.

Figure 1: PRC Meeting Content

Meeting 1: Project Background, Relationship Building, Input on Research Questions

Meeting 2: Planning Data Collection Methods

Meeting 3: Finalizing protocols and planning for recruitment.

Meetings 4, 5, & 6: Reflections on initial findings, detailed input on key themes, quotes, and recommendations.

¹ We use the term "family and child health care system" to refer to the people, institutions, and resources that deliver health care services to pregnant women, families, and children.

² See: <https://inclusioninstitute.fpg.unc.edu/sites/inclusioninstitute.fpg.unc.edu/files/handouts/early-relational-health-strategicbrief-2020.pdf>

³ See: <https://cssp.org/wp-content/uploads/2019/06/Early-Relational-Health-Webinar-6.12.19.pdf> and <https://cssp.org/wp-content/uploads/2020/05/FRAJ8069-Early-Relational-Health-paper-200526-WEB.pdf>

Commitments & Strategies for Center Parent Voices

In working with the PRCs, the researchers, partners, and funders explicitly committed to:

- putting aside our existing ideas and beliefs about ERH and authentically listening to parents' input and experiences;
- prioritizing PRC input in making changes;
- gathering information that was expected to generate more questions, rather than conclusively answer them.

Our strategies for operationalizing these commitments developed over the course of the project. On reflection, a few key processes emerged that were particularly important in our effort to engage authentic family voice within the project. These processes included:

- Building on the strength of existing positive relationships among the funder/partners (all of whom identify as White/Caucasian and bring positional power related to education level, organizational roles, and socio-economic status), the planning team was able to have open and frank conversations about implicit bias, white supremacy culture,^{4,5} positionality, and racism. These relationships helped create a context in which we could directly address how team members' white-dominant cultural practices and

beliefs were sometimes influencing dialogue and project planning. This helped the team to stay aligned with original commitments and advance equity within the project;

- Using an inclusive planning process from the start with the Research Liaisons and other research team staff of color, the planning team intentionally prioritized their input, ideas, and perspectives, including the early decisions about how to structure and support parent input that resulted in the PRC team structure, meeting content, and an approach built from parent leadership perspectives;
- Intentionally creating iterative feedback loops with the PRCs to make explicit exactly how changes were being made in the research questions, tools, and findings in response to their suggestions.
- Responding to early concerns and questions from Research Liaisons and other team members about how, or even if, the information/results would be used. Recognizing the history of white researchers "doing to" and "taking from" communities of color and providing little or nothing of value to the community, we started working very early in the process develop a dissemination plan that outlined how the partner/funders would use their networks to share information from the study.

Collecting Information From Parents

With guidance from the PRCs and using the iterative process above, we ultimately conducted three focus groups (one within each priority community) with a total of 20 mothers of young children (mothers had between 0-4 children, ranging in age from 7 months to 17 years old). PRCs helped to engage and invite other parents to these focus groups, and a number of PRCs also participated. During focus groups, parents were asked to talk about the following topics:

- What early parent-infant relationships mean to them, and how positive relationships can be established.

- Where parents go for support for themselves and their babies.
- Their experiences with, and feelings about, the role of health care providers in supporting their early foundational relationships.
- Their ideas and recommendations for how health care providers could best support families in developing strong relationships.

Specific questions varied somewhat from group to group as the PRCs provided input on how to tailor the focus group questions for each community.

⁴ Defined as: "the socio-political economic system of domination based on racial categories that benefit those defined and perceived as white. This system rests on the historical and current accumulation of structural power that privileges, centralizes, and elevates white people as a group" from: <https://uucolumbia.net/wp-content/uploads/2019/08/White-Supremacy-Definitions-August-2019.pdf>. See: <https://www.showingupforracialjustice.org/white-supremacy-culture-characteristics.html> for defining characteristics of organizational characteristics related to white supremacy culture.

What We Heard From Parents

Below we summarize some of the key ideas that we heard from parents across the three focus groups. While these shared themes are important to understand, it is also the case that more work is needed to understand the subtle (and not-so-subtle) differences in what parents have experienced and what they want most. By naming these key cross-cutting ideas, we do not mean to imply that the experiences, or root causes of experiences, of these parents are the same. Rather we suggest that there may be important fundamental shifts to paradigms, mindsets, and system structures that need to occur in order to bridge the disconnects between many families and the child and family health care system. At the same time, it seems clear that creating culturally-specific knowledge and understanding is also needed in order to create the most effective strategies through which health care providers might better support foundational early relationships. The key cross-cutting themes are summarized below.

Parents we spoke with value strong relationships with their children, and spoke eloquently about how they establish these and why they are important. **These families also see infant well-being holistically, in ways that include both physical and emotional health.**

“To me it feels like everything. It feels like the whole world. And there's always going to be struggles with everything but, to me, it feels like the whole world to be able to create and have that close bond.” [Rural Parent]

“So, I feel like being basically open with [my children] and honest with them at their level. And communicating with them at their level and making sure that they know that it's us against the world, even if I have to correct you at the house is still us against the world.” [African American parent]

“Me doy cuenta porque come muy bien, le gusta bailar, es muy activa, le gusta salir a caminar, y cuando regresa ya llega contenta. Cuando no se siente bien, se le nota, a veces llora mucho o cuando no duerme bien, llora mucho y me busca mucho también. Me doy cuenta cuando está sana porque es muy activa y contenta.” [I can tell because she eats very well, she likes to dance, she's very active, she likes to go out for a walk, and when she comes

back she's content. When she doesn't feel well, it's obvious, sometimes she cries a lot, or when she doesn't sleep well she cries a lot and seeks me out a lot too. I know when she is healthy because she is very active and content.] [Latinx parent]

Emotional support for parents is extremely important, and families tend to find this with trusted friends and family members. When these informal networks are absent, mothers shared a common experience of struggling to find needed support:

“I mean the most support I've had even since having my son is just the close support of good friends like [Friend] here and they reach out and then if I need anything, they make sure to let me know. Like, don't be afraid to reach out, but otherwise for actual somewhere you can go or reach out to and that type of thing I feel there's nothing around here.” [Rural Parent]

“Yo creo que sí me hubiera ayudado más conocer a una mamá que estuviera pasando por lo mismo que yo, que me hubiese aconsejado que hacer o qué pasos se venían. Yo creo que eso si me hubiera ayudado un poquito más, para no confundirme con tanta información que me dieron y al final de cuentas, no fue nada de lo que me estaban diciendo que podía hacer. Entonces... tal vez platicar y desahogarme con alguna mamá que estaba pasando por lo mismo.” [I believe that it would have helped me more to know a mother who was going through the same thing as me, who could have advised me on what to do, or what steps were coming. I believe that would have helped me a bit more, so that I didn't confuse myself with all the information they gave me, and in the end, it wasn't any of the things that they were telling me it could be. So, I believe that yes, maybe talking with and unburdening myself with a mother who was going through the same thing.] [Latinx parent]

“... My mom passed away and my father's never been around, so I have no parents to lean on to help me raise my kids. You would think that you could talk to your doctor. You would think that you can talk to your nurse. But when you ask questions, they either

dismiss you or they act like you're stupid for even having a question, comment or concern."

– African American mother

Parents continue to experience racism, classism and judgement in their relationships with medical providers, and frequently spoke of not “being heard.”

They shared experiences of having medical professionals discount and dismiss their concerns about their own health as well as that of their children.

“El doctor no sabía cómo ayudarme, pienso que me hubiera mejor referido a alguien más, porque es algo que le pregunté, tú crees que debo buscar ayuda diferente o buscar algún otro médico o un especialista que me ayude porque él niño no hablaba para nada y él [doctor] me decía: 'No está bien, solamente es cuestión de tiempo. ¡Todo está bien! ¡No te preocupes! todos los niños son diferentes!'. Yo soy mamá de cinco hijos, él es mi cuarto hijo, y sabía que algo no estaba bien, entonces yo creo que él [doctor] hubiera sido un poco más abierto, me hubiera dicho; sabes que no sé cómo lidiar con esto. Te voy a referir a otra persona.” [The doctor didn't know how to help me, I think it would have been better if he had referred me to someone else, because it's something that I asked him about, 'do you think I should seek out different help or look for another doctor or a specialist who can help me,' because the boy wasn't speaking at all, and he told me, 'No, it's fine, it's just a question of time. Everything is fine. Don't worry, all children are different.' I am the mother of five children, he is my fourth child, and I knew that something wasn't right, so I believe that he could have been a little more open, he could have said to me, 'you know what, I don't know how to deal with this. I am going to refer you to someone else.'"] [Latinx parent]

“I feel like they don't have this [Black women's experiences] in mind when they think of that whole concept of, 'let's create this perfect birth plan so we can make you feel as comfortable as possible.' I think that that whole idea and that whole concept is for white women and not us. It just kind of trips me out how much we are not taken care of as Black women. They dismiss us. They don't really listen to us. They have all the answers for how we need to deal with our pregnancy and our

labor and things of that nature. And it's never really like, 'How can I make you comfortable? What are your needs? What are your fears?' Things like that.” [African American parent]

“I hate going in [to see a doctor]. I have four kids, so, I mean, I've heard it a million times. Every time I take my kid to the doctor it may not be life threatening, but in the moment, it seems life threatening to me. So, I don't like when a doctor downplays it as if I'm just an overreactive parent. I think that's the one thing that irritates me the most, because, especially this is my fourth kid, most the time I know if it's serious or not. So, to be treated like I'm just neurotic kind of irritates me.” [Rural Parent]

Parents do not feel that medical providers view their child, or their family, holistically; rather they are often rushed and overly focused on specific physical health questions.

“...Me gustaría que al menos tengan el interés de tener una relación con nosotros, no andar a las carreras como solamente entrada por salida.” [...I would at least like to see that they are interested in having a relationship with us, not walking the halls, just popping in and out.] [Latinx Parent]

“Before we lived here, [...] my kids' doctor was more inclined to bring other stuff up, other than the baby's health. But since being down here, [...] it's been a huge change. I don't know if it's because my kids had a pediatrician up there, versus a family physician down here, but yeah. They don't really ask any - we talked about her health and that's been pretty much it. Besides, you know, the standard house safety rules that they have to go over about smoke detectors and car seats. Other than that, though. I mean, they really don't.” [Rural Parent]

“Yes, I do want to say that I had a hard time with doctors when I was young and I think that my kids would have more experience with hospitals and dentists and I will have a better adult record with hospitals and dentist, if they would have nurtured those relationships and made it less transactional.I think that being more personal and having time for the people, your patients. [African American Parent]

Because of these factors as well as a longstanding history of systemic racism within the medical profession, **there is considerable distrust of the medical community**, especially among African American and Rural parents:

“... it's things like that that make you feel like, ‘Well, why am I even here?’ I can figure out what my ancestors used to do to heal us [...] and just do that, because there's no point in being here if **you all** are **going to** treat us like this. I don't ask them anything anymore unless I absolutely have to.” [African American parent]

“I would appreciate it if they did not treat all of us coming in as the same exact person. I don't even just mean treating all Black people [the same]. I mean, just all people like every one of us on here that have the same ailment, but experiencing it differently. More than one of us have said, ‘I know me better than you know me. I know that you know medicine better than I do, but I know me. I have something going on, and I need your help, because I can't do it myself. So, can you just listen? Can you all please listen and not treat us like we're hypochondriacs.’” [African American parent]

When directly asked about the role of medical providers in supporting early foundational relationships, there was some notable uncertainty and some stated reservations. At the same time, however, there were some positive examples of providers whose practices reflected more emphasis on and understanding of these relationships, and **a number of parents expressed a desire or hope that their health care providers could be more supportive:**

“I feel like I'm not sure that doctors actually see that [supporting early relationships] as their role or whether they value that. I don't know. I mean, I know the data on it. So, it seems strange to me [...] I'm not sure that doctors are being taught this [the value of early relationships].” [Rural Parent]

“That whole office has been really good with, asking how we're doing, and how's it going even being a first-time mom, you know, and how stressful it is. They also have been helping with the postpartum and you know she sits there and talks to me and is like, ‘all right, do we feel we need to up it? Well, we can change to something else.’ So, I think it also depends on your doctor, like who you have and how much they actually like care to interact.” [Rural Parent]

What Questions Does This Raise for ERH?

A key purpose of this study was to raise questions that need to be addressed in order to inform the ongoing dialogue related to the role of the child and family health care system in support of early foundational relationships. To this end, below are a number of the questions that we found ourselves asking as we reviewed and discussed what parents told us.

- What is the “right role” for medical professionals in supporting early relationships? Should child and family health care be involved in this anyway? Why?
- Are there other roles within the health care model that are more appropriate than the primary care provider, such as parent educators, family support workers, community health workers, etc.?
- What needs to happen to create more opportunity for strengthening provider-parent relationships, especially in a context of historical racism and distrust? How could this happen within the time limits of a typical pediatric visit? What should change in training the next generation child and family health providers?
- Many of these mothers had been engaged with early childhood programs and services; would the responses be different for those who had not had these opportunities to engage with parenting and early childhood supports?
- What are the important cultural and historical differences that are important to understand in exploring the role of the medical community in supporting foundational relationships for different communities? How can the system ensure that important culturally-specific knowledge and shared experiences are more present in the child/family health care visit or clinic? Based on what we heard, culturally-specific differences that warrant additional attention and learning include the following, and likely many others.



African American mothers raised real concerns with how they experienced racism in the health care system. Given the long history of systemic racism in the United States and well-known abuses of African American persons at the hands of white doctors and scientists, this is hardly surprising. However, it raises other culturally-specific questions such as:

- What are the fundamental transformations that are needed in order for the historically white-dominant medical system to effectively play a trusted role for these families?
- Is there another support system or an expanded medical team (e.g., family peer mentors, community health workers) that could better support these early relationships between parents and their babies?



Latinx mothers seemed to be more receptive and open to help from their medical providers, although they also shared negative experiences. They were also more likely to talk about the importance of physical health, and supports they had received from the health care system. Latinx mothers also described their concerns with getting appropriate help for children with special health care needs, and in making sure children were developing specific language and cognitive skills that they may see as critical for their children to be school-ready.

- Were these findings specific to these women, most of whom were of Mexican immigrant descent? For example, rural White mothers also stressed the importance of very early language development activities.
- What more nuanced cultural understandings are needed to understand diversity within Latinx families and their beliefs, attitudes, and experiences with health care providers?



Rural White mothers emphasized strained relationships with medical providers, geographic isolation, and the need for more connection to peers and informational supports. These mothers also implied that most health care professionals had little understanding of the challenges of living in remote, rural areas and felt their providers were not interested in the holistic health of their family or baby.

- Do these perspectives represent broader rural parent experience?
- What would it take to create empathy and understanding of the challenges related to accessibility for rural parents?
- While some rural parents want their medical providers to focus on the whole family and take an active role in supporting these early relationships, there may be better alternatives for families who will never trust the medical system. What are those alternatives? Are there opportunities to build peer-to-peer supports for new parents who are extremely isolated?

Where Do We Go From Here?

In order for innovators and leaders to advance early relational health within child and family health system transformation, additional family voice and feedback will be critical to advance trust, cultural sensitivity and meaningful partnerships in support of family experiences. This pilot study brings many important insights to that journey, and the voices of these parents adds to existing calls for medical providers and the health care system to change how they work with families. Parents made several specific recommendations for changes in the child and family health care system that would help build better trust and support:

- Training and supporting the child and family health care workforce to value and respect the rich culture and experiences of all parents, and recognize the strengths and resiliency that they have as parents of their children and as the person who best knows their own, and their child’s needs and experiences;
- Creating time, capacity, and skills within the health clinic and provider-family visit that can better support respectful relationships and build trust with families, for example, by providing empathy training for child and family health care providers⁶;
- Changing current systems to facilitate structures and professional practices that are holistic and culturally sensitive;
- Improving the ability to listen and be responsive to parents’ concerns and questions, and approach

parents’ questions with an attitude of curiosity and wondering, rather than from a position of expertise;

- Seeking and using authentic feedback from clients/patients about their experiences in the clinic for ongoing processes of improvement and partnering with families.

Finally, it is important to note that changes to the health care workforce were noted by all parents as important for creating change in the system. Clearly, building a more culturally and linguistically diverse future workforce, and one which includes more providers who share the lived experiences of a more diverse group of families will be a critical long-term strategy for more effectively supporting families who have been historically marginalized. African American and Latinx mothers stressed the need for more bilingual and medical providers of color and who specifically “look like them”. Rural families emphasized the importance of having medical providers who understand the unique challenges that social and geographic isolation create for rural families. As professional pathways for a more diverse workforce are created, however, systems change is needed that can support and facilitate more trusting relationships between parents and providers. These changes are essential before the child and family health care system can hope to most effectively support parents in their foundational relationships with their children.

⁶ A model for this type of relationship- based training for health care providers is the “Communicating with H.E.A.R.T” program operated by the Cleveland Clinic; for more information visit:

<https://my.clevelandclinic.org/departments/patient-experience/depts/experience-partners/licensed-programs/communicate-with-heart>