

Yale University

## EliScholar – A Digital Platform for Scholarly Publishing at Yale

---

Public Health Theses

School of Public Health

---

January 2022

### Caregiver Experiences Of Social Need And Promotion Of Support In The Pediatric Setting: A Qualitative Study

Meghan Patricia Casey  
meghancasey10@gmail.com

Follow this and additional works at: <https://elischolar.library.yale.edu/ysphtdl>

---

#### Recommended Citation

Casey, Meghan Patricia, "Caregiver Experiences Of Social Need And Promotion Of Support In The Pediatric Setting: A Qualitative Study" (2022). *Public Health Theses*. 2139.  
<https://elischolar.library.yale.edu/ysphtdl/2139>

This Open Access Thesis is brought to you for free and open access by the School of Public Health at EliScholar – A Digital Platform for Scholarly Publishing at Yale. It has been accepted for inclusion in Public Health Theses by an authorized administrator of EliScholar – A Digital Platform for Scholarly Publishing at Yale. For more information, please contact [elischolar@yale.edu](mailto:elischolar@yale.edu).

**Caregiver Experiences of Social Need and Promotion of Support in the Pediatric Setting:  
A Qualitative Study**

Meghan Patricia Casey

A Thesis Submitted in Candidacy for the Degree of Master of Public Health

Department of Social and Behavioral Sciences

Yale School of Public Health

First Reader: Danya Keene, PhD

Second Reader: Martha Swartz, PhD, RN, CPNP, FAAN

May 2022

## Abstract

Children are vulnerable to the long-term health impacts of unmet family needs within social determinants of health like income, food security, housing, and transportation. Efforts have grown to recognize and respond to these challenges in the pediatric setting through social needs screening and other interventions. Previous research has extensively described the pediatric provider perspective on this work. However, less is known about how caregivers experience interactions surrounding social needs in the healthcare setting and which factors may influence these perceptions. To address these gaps in knowledge, this qualitative study examined semi-structured interviews of 20 caregivers who participated in a pediatric medical-legal partnership program. The author inductively coded and analyzed the data using Dedoose. Findings examined caregivers' lived experiences navigating social needs, the impact of these underlying histories on interactions with their children's medical providers, and factors facilitating feelings of support within the provider-caregiver relationship. In their experiences of social needs, caregivers often felt stressed, stuck, alone, and ignored. They often downplayed or withheld their challenges from providers due to fear of misjudgment as a bad parent, fear of DCF reporting, previous negative experiences, feelings of disrespect, perceived negative assumptions, and stigma. These were drivers of distrust. Continuous opportunities for engagement, displays of genuine care, and construction of partnership fostered feelings of support, trust, and comfort among caregivers. Experiences shaped both perceptions of individual providers and the healthcare system more broadly. These findings can aid pediatric providers in promoting feelings of support among families experiencing social need by informing their approach as they structure conversations, build trusting relationships, and respond to identified needs.

### **Acknowledgements**

First and foremost, I would like to thank the caregivers who took the time and energy to share their experiences in these interviews and whose stories I will always carry with me. I would like to thank Danya Keene for her unconditional guidance and assistance throughout this project, supporting me professionally and personally. I am deeply grateful to Marty Swartz for her support, flexibility, and willingness to provide insights from a clinical perspective. I would also like to extend a special thank you to Judith Chubb, Dr. Shannon Shea, Alex Massawe, Thomas Roche, and Dr. Benjamin Oldfield, individuals who have uniquely inspired and nurtured my passion and belief in the critical importance of social factors in families' ability to thrive. Lastly, I would like to thank my husband and family for loving me, believing in me, and lifting me up on my best and worst days.

## Table of Contents

Introduction.....	5
Methods.....	11
Findings.....	13
Navigating Experiences of Hardship.....	14
Negative Caregiver Framing of Pediatric Health Interactions .....	19
Facilitators of Support and Positive Relationships .....	24
Discussion.....	32
The Value of Contextual Knowledge of the Caregiver Experience .....	32
Drivers of Distrust and Disengagement .....	34
Promoting Experiences of Support .....	38
Policy Implications.....	46
Limitations .....	48
Conclusion.....	49
References.....	50

## Introduction

Children are vulnerable to the long-term health impacts of unmet family needs within social determinants of health (SDOH). For this reason, efforts have grown to recognize and respond to these challenges in the pediatric setting. Previous research has extensively described provider perspectives on this work. However, less is known about how caregivers experience interactions surrounding social needs in the healthcare setting and which factors may influence these perceptions. A helpful first step in refining and approaching this gap is taking time to understand these social needs, their impact, current efforts, and existing literature.

Social determinants of health (SDOH) are defined by the World Health Organization as “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life” (World Health Organization, 2022, para. 1). The statement’s latter half encompasses high-level economic and social policies, institutional systems, cultural norms, and historical context. The first part, however, zooms in on individual, household, and community factors like income, food security, and housing that people tangibly see and feel in their daily lives. The concept of these factors as “determinants” stems from their well-documented association with various health outcomes. Children are particularly sensitive to these impacts, with unmet social needs placing them at increased risk for chronic illnesses like asthma and depression (Thomas et al., 2019), impaired behavioral functioning (Coley et al., 2013), elevated emergency department utilization (Conroy et al., 2021), decreased access to healthcare (Peltz & Garg, 2019), significant school absenteeism (Peltz & Garg, 2019), and other negative sequelae that reach far beyond their childhood years (Council on Community Pediatrics, 2016; Drennen et al., 2019; Dwomoh & Dinolfo, 2018). These health risks are cumulative

(Larson et al., 2008), suggesting that social needs build upon one another to position children within a gradient of increasing vulnerability.

This knowledge is concerning given the high prevalence of social needs among the pediatric population and the likelihood that families will encounter multiple needs concurrently (Centers for Medicare & Medicaid Services, 2020; Gottlieb et al., 2016). Around 1 in 6 children are currently experiencing poverty, the highest rate of any age group nationally (Parolin et al., 2022; Shrider et al., 2021). Most recent data from the U.S. Census Bureau's Household Pulse Survey found that almost a third of households with children described themselves as at risk of eviction or foreclosure over the next two months (United States Census Bureau, 2022). For many families, the COVID-19 pandemic has either exacerbated existing needs or pushed them into conditions of hardship for the first time (Abrams et al., 2022; Alamilla & Cano, 2022; Body et al., 2021). For instance, estimates show that overall food insecurity among households with children rose from 14.6% in 2019 to nearly 20% in 2020 (Hake et al., 2021). Although 2021 data are projected to lower to 18% (Hake et al., 2021), this number still represents an increase over pre-pandemic circumstances and may point to long-term amplified impact (Leddy et al., 2020; Wolfson & Leung, 2020).

Considering the prevalence of social needs and their powerful link to negative health consequences in children, a growing push has developed for the healthcare field to adopt a more active role in recognizing and responding to these challenges. Innovations like needs navigation programs (Gottlieb et al., 2016), mobile health clinics (Taylor et al., 2016), and other initiatives (Gottlieb et al., 2017) have shown promise in potentially decreasing need and improving outcomes. Another increasingly popular model is that of medical-legal partnerships (MLP). MLPs are programs that integrate medical and legal care by providing otherwise inaccessible

attorney services to patients with health-related needs in areas like housing quality that may be improved through legal support (Keene et al., 2020). Yet another approach is a focus on feasibility and sustainability through design and implementation of alternative payment systems (Alley et al., 2019; Melzer, 2022).

Screening processes using tools such as WE CARE or the Survey of Well-being of Young Children often precede these endeavors (Henrikson et al., 2019). This practice aims to identify which families are experiencing social need and could benefit from further support. This step is critical as screening may result in higher rates of referral to cross-sector services and increased utilization of community resources (Garg et al., 2015). Pediatric healthcare providers (HCPs) in particular are strategically well-positioned for the task of screening given their expertise in child development and extended regular contact with families throughout the well child visit series (Bright Futures, 2019, 2021). Even in the absence of formal referral systems, screening by pediatric HCPs is still mutually valuable as it allows clinical plans to be designed within the context of a family's reality and promotes accurate and effective care (Smith et al., 2008; Tong et al., 2018; Weiner et al., 2010).

Despite general HCP agreement with the importance of SDOH and related screening, many do not incorporate such work into their practice (Fraze et al., 2019; Garg et al., 2019). For example, Barnidge et al. (2017) found that while 88% of pediatric providers believed that food insecurity was a challenge for their patients, only 15% went on to screen for this need. To explore this disconnect, previous research has extensively described the pediatric provider perspective surrounding screening. This work has identified barriers such as time constraints, discomfort with an inability to ensure that needs are met, concern that such topics might offend patients, and skepticism that HCPs should be the ones assigned screening responsibilities



(Barnidge et al., 2017; Byhoff et al., 2019; Hamity et al., 2018; Kostelanetz et al., 2021; R. Sokol et al., 2019; R. L. Sokol et al., 2021). Many additional studies have centered on investigating which tools and delivery methods are most effective and acceptable in the pediatric setting (Cullen et al., 2020; Knowles et al., 2018; Oldfield et al., 2021; R. Sokol et al., 2019).

Perhaps because of this functional focus on improving provider participation, less is known about how caregivers themselves feel approaching topics of social need. Many studies have described parents' experiences moving through specialized facets of the health system in the context of their children's particular acute or chronic conditions like inflammatory bowel disease (Giambra et al., 2018), autism (Boshoff et al., 2018), medical complexity (Lin et al., 2020), and end of life care (Bennett & LeBaron, 2019; Butler et al., 2018). Little research has focused specifically on parental healthcare experiences in the context of underlying social need. Work that does cover this topic tends to narrow in on the screening process and results. For example, some caregivers report feeling uncomfortable even though screening acceptability appears to be high among the general caregiver population (Byhoff et al., 2019; Cullen et al., 2020, 2022; E. H. De Marchis et al., 2019). This unease may be highest among parents who actually endorse social needs (Barnidge et al., 2017; Cullen et al., 2022). This suggests that general acceptability may not always be a meaningful goal if the uncomfortable minority includes the very people the intervention is aiming to help. Additionally, screening in and of itself does not necessarily translate to a willingness or desire to subsequently engage with HCPs about identified needs. Studies report that almost half of caregivers with positive results decline to discuss these challenges with their child's provider (Zielinski et al., 2017). An even greater proportion answer negatively when asked if they would like assistance (Tong et al., 2018).

A few qualitative studies from the caregiver perspective outline fear of judgment and institutional consequences like involvement of Child Protective Services (CPS) as possible drivers of this discomfort and distance from HCPs (Barnidge et al., 2020; Cullen et al., 2020; Knowles et al., 2018; Palakshappa et al., 2017; Schleifer, 2020). Further research in this area is critical. The need for additional exploration of this discomfort does not reflect a paternalistic assumption that caregivers unequivocally want or need HCP involvement. Instead, it highlights the concern that these reactions could represent a deeper rift in the caregiver-provider relationship that is creating missed opportunities for support. Identifying active facilitators of positive interactions will also be helpful in better defining best practices that HCPs can work towards implementing. Two factors that may improve comfort are strong caregiver-provider relationships and HCP transparency surrounding screening (Cullen et al., 2020; Schleifer, 2020).

Another gap in the existing literature is the lack of caregiver accounts surrounding what navigating these challenges looks and feels like in their daily lives. Exploring these nuances may promote empathy and genuine connection by expanding HCP appreciation of social needs beyond associated risks to the functional and emotional impact on families (Tong et al., 2018). Although caregivers are far from homogenous, identifying common themes across narratives can also foster a clearer understanding of the lenses through which they may construct their thoughts, beliefs, and behaviors. Knowledge of this framework ultimately begets richer analysis of how HCPs' words and actions interact with these lived experiences to shape caregiver perceptions of visits, relationships, and the healthcare system more broadly. A fuller understanding of what caregivers may be going through is also relevant to pediatric care considering that caregiver well-being and the related capacity to develop and maintain protective, positive relationships have direct impact on their children's ability to thrive (Conn et al., 2020; Partap, 2019).

To address these gaps, this qualitative study used semi-structured interviews to capture the narratives of 20 caregivers of children who participated in a pediatric MLP program. Through these caregiver accounts, the study aimed 1) to better understand caregivers' lived experiences navigating social needs; 2) to explore the impact these personal histories may have on how they approach and perceive related interactions with their children's HCPs; and 3) to identify factors that may actively facilitate positive feelings of support within that context. This knowledge will ultimately contribute to identification of ways that pediatric providers can more effectively and sensitively foster feelings and relationships of support among families experiencing hardship.

Although some HCPs may have used screening tools to connect caregivers to the MLP, this study emphasized the general concept of pediatric HCP involvement in families' social needs rather than formal screening processes exclusively as many others have done. By nature of their involvement in the MLP, this study centered on caregivers who had experienced social need. This is an important focus given that this population may be at highest risk for negative perceptions within healthcare spaces (Barnidge et al., 2017). Because they are less likely to engage, these families may also be excluded from connection to resources more often (Cullen et al., 2022). Examining these experiences can thus contribute to health equity. Furthermore, most previous qualitative studies from the caregiver perspective have focused specifically on food insecurity (Barnidge et al., 2020; Cullen et al., 2020; Knowles et al., 2018; Palakshappa et al., 2017). This study purposively recruited caregivers to reflect a diversity of needs. Lastly, little to no research has been done on these topics within the setting of an MLP program. Caregiver narratives inherently covered their interactions with the MLP lawyer. These parallel relationships

provide a valuable opportunity to identify positive or negative factors that may be applicable across sectors.

### **Methods**

This study involved a secondary qualitative analysis of in-depth semi-structured interviews with 20 caregivers of pediatric patients. All caregiver participants were current or previous clients of the Medical-Legal Partnership at Yale-New Haven Children's Hospital in New Haven, Connecticut. This patient population is primarily low-income. The program is housed within a primary care center and run through the Center for Children's Advocacy in partnership with the hospital. This particular pediatric MLP employs one lawyer and implements an integrated model in which the lawyer is stationed full-time within the clinic. This allows for access to real-time referrals, consults, and informal check-ins throughout the day. In addition to providing services to families, the lawyer leads educational efforts for clinic providers surrounding health-harming legal and social needs that may impact patients. At the time of initial data collection, the MLP was in its sixth operational year with nearly 1,500 patient referrals.

The only inclusion criterion for participants was their status as caregivers who were previously or currently engaged with the pediatric MLP. The MLP lawyer led initial identification of potential participants by providing a list of clients. Researchers then employed purposive sampling throughout the recruitment process in an attempt to diversify: 1) case types across needs like housing, utilities, government benefits, and education, and 2) level of MLP legal intervention, ranging from brief consultation to full representation. Recruitment letters were sent out to 169 former or current clients, with approximately 10% failing to reach their intended targets due to incorrect addresses. Another 10% (N=18) of letters resulted in completed

interviews. Two additional participants, one recruited through snowball sampling and the other directly through the MLP lawyer, brought the final sample size to 20 caregivers.

Of these 20 caregivers, 18 were parents and 2 were grandparents of pediatric patients. All participants were females, a reflection of the MLP's heavily female client population (>90%). All caregivers were women of color, with 70% identifying as Black, 25% as Hispanic, and 5% as Other. Average age of participants was 40 years. The majority of caregiver participants initially became involved with the MLP due to needs surrounding education (35%) and housing (30%) followed by utilities (15%), government benefits like Supplemental Security Income and nutrition assistance (15%), and guardianship (5%). Average time since interaction with the MLP program was 27 months, a little over 2 years.

Two researchers conducted semi-structured interviews from July 2018 to May 2019. An open-ended interview guide was utilized to provide general direction and ensure that primary topics were covered while still maintaining participant freedom to share what they felt was important. Baseline questions covered topics surrounding experiences with the MLP, other history working within the legal system, child and caregiver health, relationships with pediatric providers, and the impact of services on these relationships. Two interviews were conducted in Spanish and the rest in English. Interviews ranged from 20 to 74 minutes in length with an average of 45 minutes. They were recorded and professionally transcribed. Participants were compensated \$50 for their time. The Yale University Institutional Review Board approved all recruitment, data collection, and analysis procedures.

Primary data analysis began with collaborative group discussion among the research team to identify general overarching themes. A grounded theory approach was then applied to inductively develop a coding scheme based on these emerging concepts. This process was

iterative, with researchers meeting regularly to refine codes until they reached final agreement. Two coders then applied the codebook to each interview transcript, using Dedoose software to organize and manage the data.

In this study's secondary analysis, the author reviewed all excerpts related to relevant codes. The author then read all transcripts in their entirety to gain full context, understand overarching narratives, and identify additional codes related to caregiver experiences. The author went through all transcripts a second time for iterative refinement of these supplemental codes. Lastly, these data collectively informed the forthcoming findings. Pseudonyms are used throughout the work to protect participant identity.

### **Findings**

Most caregivers in this study experienced a variety of overlapping social needs that created constant stress and increased baseline vulnerability. Participants poured extensive energy into finding solutions to protect their children. In these efforts they often felt stuck, overwhelmed, lost, alone, helpless, and ignored. In interactions with their children's HCPs, caregivers often downplayed or withheld information about their needs because of fear of misjudgment as a bad parent, fear of DCF reporting, and past negative experiences. Stigma, perceived assumptions, and feelings of dismissal also contributed to this distrust and discomfort. Despite these negative perceptions, some caregivers developed strong relationships with their children's HCPs. Continuous intentional opportunities for engagement surrounding social needs were a critical first step. Small actions of support and intangible displays of care contributed to building trust even when the HCP could not broadly address underlying needs. Building partnership within the caregiver-provider relationship further strengthened trust and empowered

caregivers as equal partners in care. These experiences shaped both perceptions of individual providers and of the healthcare system more broadly.

### **Navigating Experiences of Hardship**

In this study, all participants encountered some level of hardship. Most caregivers did not identify one single need but instead described the daily grind of multiple interconnected challenges. This network of synergistic baseline needs often generated constant chronic stress. Fatima, an immigrant mother of four children, spoke about the competing priorities she must consider in her struggle to meet the family's needs every month: "If you pay your rent, you don't get nothing. And to have kids, pay your light bill, your gas bill for only \$1,000 a month. Sometimes the food stamps they give you is not enough.... You've got to buy kids' clothes, shoes.... They're girls, they're getting big. Sometimes it's tough. But you do what you can." Caregivers' repeated contact with the MLP suggested that these challenges may shift in priority or differentially emerge over time. For example, one mother described receiving help over multiple years with services like medical cabs, school advocacy, utility assistance, and housing quality control. Because caregivers were stretched so thin by these demands, seemingly small stressors often had outsized impact. One participant described how each logistic step of her son's frequent medical appointments quickly added up to create strain:

I have to pay for gas, I have to pay for parking, I have to pay for food. Sometimes I'll be there all day.... The car that I had broke down on me. I did a quick, last-minute decision, and I got into a payment plan with the car, which I need anyway because I need to be able to take him to his doctor visits and his blood work.... I can't depend on anybody to take me or anything like that, so yeah.

This context created an environment with very little cushion for families to absorb the blow and cope with the stress of more acute events like job loss or hospitalization of a child. These events often brought caregivers to a point of feeling overwhelmed with all they were trying to balance. This was the case for Nia when she was in the hospital and facing eviction: “I was so overwhelmed between the cholestasis, the diabetes, the constant checking of the sugar, the constant monitoring of the baby and, you know, and then on top of that worrying about, okay, when I do come outta this hospital will I have a place to live?.... What’s gonna happen next?” In response to this stress, caregivers often prioritized their families and pushed themselves to the side. Jasmine, whose son was born with the serious condition of biliary hypoplasia, described how this unforeseen challenge compounded the stress of her existing responsibilities and diminished her ability to care for her own well-being:

This bill is coming up. There's the rent. Bills, and plus the other two kids I needed to keep an eye on and make sure, remember, because I felt like a blockage where I was so focused on him that I wasn't really paying attention to anybody else, even to myself.... I wasn't eating right, I wasn't sleeping, I wasn't doing anything.... I would not sleep thinking that he was going to die on me.

Jasmine’s husband left the family during this stressful period, further escalating the precariousness of their financial state. She is now facing eviction. Although this experience would be difficult for anyone, preexisting social needs made it even harder for families like Jasmine’s to successfully adapt and regain stability when unexpected or acute situations arose. As a result, consequences of these events tended to be serious and were more likely to push families into crisis.



Many caregivers described feeling stuck in these situations, desperate to find a solution for their families yet unable to do so with current resources. The desire to protect their children formed the foundation of this pressure. Jessie, a single mother of twins, lives in an apartment with an out-of-control bug infestation and no temperature regulation in a neighborhood where street shootings are common. She talked about the resolve she felt patching up the window during wintertime and the disappointment she then endured with each passing year: "It's routine every year and I always tell myself, 'Next year you're not going through this, Jessie.' Nope. 'Hey, kids, we're stuck here again. Brace yourself. Go put on two socks. Go put on three pajamas.'" She detailed her increasing stress and exhaustion: "It's just too much. It's put a big hole in my life. All these years I've been stressed out living here.... I just feel like so desperate at times." For caregivers experiencing long-term social needs, stress often became a normal fixture of their daily lives rather than an isolated circumstantial emotion.

Many caregivers' narratives expanded on the concept of stress to more fully describe how they felt in this process of navigating the search for solutions. Several participants recounted feeling lost or unsure of where to start when trying to work through these problems alone. This uncertainty often combined with their urgency to help their children to create a sense of helplessness. Tiana, a mother of four, described this overwhelming feeling:

You have all these problems going on with your children, and you don't know where to turn.... It's like, trying to do it on your own, you don't know which way to go. You don't know where to start, where to stop, what to tell, what not to tell. Because you're just pulling something up on Google.

Maya, whose son was born with a rare metabolic disorder, experienced the same anxious confusion surrounding finding a resolution when the only resource seemed to be a trove of

Internet information: “The whole law system is very overwhelming for someone that doesn’t know what they’re doing. And then you go on Google, it’s like overload information. You don’t know what’s true, what’s not true, and there’s curves to this or loopholes to that.” This process became isolating for many caregivers. After months of advocating for better housing quality, Tiana began to feel like she was on her own in these struggles: “It got to the point where I felt like I was alone. And like, a lot of people's like, ‘How do you feel alone? You got children, your husband, and so and so.’ I’m like, ‘You’re not understanding.’”

Despite emotions of uncertainty, helplessness, and isolation, caregivers continued to move forward in their efforts to pursue a better situation for their families. Most reported dedicating extensive time and energy to finding help by making calls, researching, and going to meetings amid their other responsibilities. One mother described that she has been unable to find alternative housing options despite the work she has poured into avoiding eviction. She has been on the Section 8 waiting list for ten years. When asked how much time she spends every week on such efforts, she used her experience from that very morning as an example:

I called Friendship Center... I called up a church that 211 referred me, ‘go to Google, go to the yellow book, and start calling all the churches’ because they didn't have a listing to verify which one of those helps with fundings.... HRA tells me, ‘Oh, we no longer do that. We no longer help with security deposits or rent, whatever issues’.... I spent all day today. Since 8:30. I called 211 and I left a message. While the person decides to call me, I did texting with 211.... I had the person on the phone call on speaker telling her what I wanted them for, and she's answering while I'm still texting with someone else. The one that I was talking to didn't find anything. ‘Sorry. Bye.’ The one I was texting gave me the two phone numbers, which is the HRA and Friendship Center... Yeah, so that was that.

Many caregivers shared similar experiences with feeling like their endeavors ultimately provided little tangible relief. Some, like the mother who described her calls, became disillusioned as support staff seemingly sent them in circles. Others recounted frustration at feeling entirely ignored as they tried to advocate for themselves and their families. Tiana's daughter ended up in the hospital with black mold poisoning and now struggles with long-term health concerns. She tried to push from the start for her landlord to address their poor housing conditions and described feeling angry and exasperated that her worries were ignored:

And the thing that upset me was that I had called—where we used to live, I called them and was letting them know when she was 6 months that I kept smelling something funny. And they was like ‘oh that’s just the water from the washer draining.’ I’m like no.... I know what dirty water smells like. This doesn’t smell like dirty water.... The lady that was trying to evict us, she was like, ‘Oh, you never called in about nothing. You never let us know.’ And I'm like, yes, I did. More than once. I said, I've been telling you all this since my baby was six months.

Some caregivers believed that this dismissal stemmed from an inferior position of power and lack of respect. Sequoia, whose son suffers from severe asthma, shared her experience advocating for carpet removal to help his condition: “Because I live in low-income housing, he brushed me off.... He refused to. He said he’ll get around to it. He said he would think about it. He said he would give it some thought. A year went by.” Many felt that others took their efforts seriously only with support from individuals who had more institutional weight. Caregivers appreciated finally making progress, but they also felt frustrated that people took advantage of them. Sylvia, a mother of premature twins, described a complete change in her landlord's demeanor after months of trying to handle the situation on her own:

My apartment, the people upstairs must be left they water on, or they turned the air off or something last year. And they bust the pipes and the whole thing came in from upstairs.... Yeah, so I had to call the lawyer because my landlord wanted me to still pay the rent and I wasn't staying here. So he was like, 'Oh, but I still need it.'.... So the lawyer, soon as she called him everything changed.... As soon as he hear, 'Oh, I'm an attorney from Yale,' that's when he, 'Oh hey, how you doing?' Everything change.

Charlotte is a mother who was incorrectly told for months that she was not allowed to sign up her child for school without an ID. She finally resolved this issue when she had the force of the MLP lawyer behind her. She summarized this power imbalance when discussing her drawn out advocacy efforts: "In the back of my mind, you always know that if you don't have the authority then 9 times out of 10 you really don't hold any weight."

### **Negative Caregiver Framing of Pediatric Health Interactions**

Data suggest that an omnipresent fear of misjudgment as a bad parent permeated caregivers' interactions with pediatric providers. For many, this fear was connected to feelings of shame surrounding the perception that they could not care for their families. Nia reflected this worry of HCP judgment when she expressed feeling embarrassed at the thought of disclosing her situation. She had significant complications towards the end of her pregnancy that necessitated near-daily appointments, a circumstance that made it difficult to work and pay rent. She described how she felt during that time and her associated hesitancy to ask for support:

I didn't feel comfortable bringing it up, you know? I didn't feel like—I didn't feel comfortable with letting anybody in on what I was dealing with.... I'd never had this predicament before, you know? A second child, been outta work for a while and it was

just—it was almost embarrassing, because it's like okay I'm 36 years old, I have a child at home and even have one on the way and no income is coming in, you know?

The idea of being assigned the label of incapable parent was particularly hurtful given the extensive efforts caregivers made to prioritize their children. A single mother of three, Sara worried that her children's HCP might categorize her negatively if she shared her challenges: "I'm not the type to ask for help.... I try not to ask too many people for things. So, it was more like pride and shame because it was like, it looks like I can't take care of my children, but it's not that. It's just that I didn't have – I had lost my job because I was pregnant. So, I couldn't work. I couldn't do much." Like Sara, many caregivers felt that an HCP who did not understand the complexity of their situation would define them by their challenges alone.

Caregivers also feared being framed as a bad parent because of the potential for real consequences within their families. Given HCPs' heightened position of power within the child welfare system, many participants worried that poor perception of their parental capability would result in a report to the Department of Children and Families (DCF). Many were anxious that opening up about their struggles to HCPs could give rise to harm and disruption instead of support and relief. Kylie, mother of an 8-year-old with special needs, was wary that her experiences might be manipulated negatively by HCPs: "I don't feel like I'm going to talk to every and anybody, 'cause I won't. It just won't happen.... Cause like, I don't like telling people my business, cause some people use it against you, and I don't have time for that." Sequoia described a similar fear when initially disclosing her situation to the MLP lawyer, another institutional figure: "Sometimes, I would be afraid that it would backfire on me." Yet another mother described her anxiety surrounding this potential for action: "I was really worried that the

doctors might call DCF or something like that like, ‘she can’t take care of her children.’ I was really worried about it.”

In response to these fears, many caregivers either avoided sharing or actively downplayed the hardships they were experiencing. When asked whether there were times when she thought about asking for help and decided not to for this reason, Sara answered: “Mm-hmm. So I just dug myself into a deeper hole.” Some caregivers like Marlana were unsure who they could feel safe sharing their lives with, especially when they did not have a consistent provider relationship. This uncertainty created caution and distrust within conversations about social needs: “You get a different personality every resident.... Who you can and can’t or you don’t want to say—not don’t want to say too much like you’re trying to hide something, but everybody’s different.”

For some participants, fears of reports to DCF were rooted in their own past experiences. These DCF encounters spanned various outcomes and levels of involvement. Kendra’s child was in an accident that occurred under the care of his separated father. The event left him completely physically dependent. Even though she knew the tragedy was not her fault, Kendra detailed the pressure and scrutiny she felt during DCF investigation of her home. The high stakes environment left her feeling overwhelmed with little room for flaws: “That was a lot because I was going through enough already trying to make sure he stays alive and trying to keep myself sane.” Others had deeply traumatic and life-altering memories associated with DCF. Kylie described the removal of her first two children from her care as a teenager. She recalled recently learning about reorganization within DCF that aims to better identify and resolve underlying family needs. Despite these changes, she expressed that she will never have faith in the agency as a positive source of support: “I said, well about damn time, but I still don’t trust DCF. I still don’t trust them. And I won’t. Ever. I don’t think that there’s a bone in my body that would make

me trust them.” Kylie and other caregivers strongly viewed HCP filing of a DCF report as a statement of negative judgment rather than as an attempt to help the family.

In some cases, caregiver reluctance to engage extended beyond general anxious uncertainty into active belief that HCPs would work against them. In the most explicit narratives of distrust, caregivers framed pediatric HCPs as adversaries they would never turn to in a time of need. These fears and experiences surrounding DCF often directly contributed to baseline skepticism. Kylie, the mother who had two children removed from her care years prior, made this connection clear in her assertion that HCPs would immediately call DCF. She was more comfortable with the MLP lawyer as she felt the lawyer would engage with her rather than automatically turn the conversation to reporting: “I don’t trust them [providers].... They’re DCF. I don’t trust them. Like, honestly, I deal with them ‘cause I have to—but other than that, no. I’m not dealing with them.... She’s [the lawyer] mandated, too, but she don’t, you know, every time you talk with her about something it’s not, ‘I’m about to call DCF on you,’ you know what I’m saying?” Another caregiver, Jessie, described a recent instance when she thought about seeking help after her daughter came home from school with an injury inflicted by a teacher. She chose not to as she felt certain that HCPs would accuse her instead of helping: “When I took off that bandage, I wanted to run to the hospital. I had nowhere to run. Had I ran to that hospital they would have thought it was me.”

Distrust also stemmed from the perception that their children’s HCPs held pre-established negative assumptions about caregivers. This was often a stigmatizing experience as caregivers felt that HCPs had already formed opinions despite hardly knowing anything about them or their lives. Amy, a mother of three children, interpreted the questioning from her child’s HCP as a sign that they already suspected certain answers:

When she asked me, ‘Do you feel safe at home?’ I’m like, ‘Do I look stressed out? Do I have bruises? Do I look beat up?’.... I get it, they have to ask those questions. But also, it makes someone feel that they’re looking at – they’re judging them and looking at someone as – you know what I mean?.... I get it. They have a lot of people that come from all places. I just feel when somebody – it kind of feels insulting. You know?

Many caregivers also perceived that the end goal in conversations about social needs was not to support them but to attack their “weaknesses.” This impression made negative interactions feel even more intentional by providers, putting caregivers on the defensive rather than encouraging them to share their needs. When asked whether she was comfortable answering questions from her child’s HCP about their social situation, one mother described feeling like the probing may be an attempt to bring her down: “It depends on the question and depends on if I’m gonna get offended by the questions.... I don’t like to be- I don’t like to feel like I always have to put my guards up. And I do. Like, I always feel my guard’s up because I feel like somebody’s going to come at me.” Preemptive defensive reactions like this one hinted at the belief that provider intentions were not necessarily benevolent.

Although many caregivers discussed expectations or encounters of actively negative HCP reactions to conversations about their social needs, a few reported experiences of simple dismissal. These participants often felt that their children’s HCPs simply did not seem to care much about what they shared. One mother stated: “You got some people that brush you off.” This led some caregivers to feel unheard in their interactions. Marlena recounted a frustrating visit with her own provider: “I had a doctor not too long ago for myself. He just kind of shrugged off all of my symptoms as, ‘oh, whatever, It’s fine. You’re fine.’ It’s like, no, I’m not fine. I’m trying to tell you that I’m not fine. But you’re not listening to me.” These experiences decreased



caregiver confidence in the value of sharing their struggles or asking for support in that setting. Indeed, some participants reported that reaching out to HCPs was no more useful than being on their own. Jasmine, the mother who spent hours making housing calls, described a conversation with her child's HCP that she perceived as condescending. He seemed to chastise her, telling her that her son should not be unstably housed as though she was willingly choosing the situation. He also failed to ask her about her own efforts to look for solutions, rendering his suggestions out of touch and offensive:

I let them know the situation and stuff like that. Not only do they tell me, 'he cannot be in a shelter due to health issues,' but yet, 'we can't help. Try 211, try to look for resources, Google, and try to look for resources around your area.' That's pretty much their answer, which is like I might as well talk to the wall.... 211 doesn't help unless I'm already in the streets over 5 days, like that doesn't make any sense. We're trying to avoid that.

### **Facilitators of Support and Positive Relationships**

The practice of simply asking what was going on in their lives through screening or informal conversations was critical to caregivers eventually disclosing their challenges. Almost all participants received help and support from the MLP lawyer or HCPs only after someone on their health care team specifically asked about their needs. Only one mother appeared to bring up her family's challenges on her own accord. When HCPs did not take this step, they often remained unaware of what was going on behind the scenes in their patients' lives. For example, Sara lived for years in a housing complex that went through a highly publicized crisis due to dilapidation and unsafe living conditions. When asked whether her child's providers inquired about what was going on at that time, she recalled that no one asked until she needed supporting documentation to move during city demolition: "I think they only did when I had to go get the

kids' medical papers and stuff, that's when they started asking like, 'what's the problem?' and stuff." Fatima described living without heat in her cold New England home for nearly two years. She finally accessed assistance programs after her HCP asked some questions and offered help connecting her to services. No one had ever asked about her social situation during the previous two years. She expressed joy that this interaction took place: "I said, Oh God. How he know my problem? He just think about my problem.... I thank God to make that guy come ask me all these questions."

Caregiver narratives also highlighted the importance of consistency in asking these questions over time. While Fatima was quick to disclose her worries in conversation, several other caregivers expressed their needs after continuous opportunities to do so. One mother described finally feeling ready to ask for support despite past reluctance:

They usually ask the question, 'if you need help, let us know what we can do for you,' or whatever. So I was like, I need some help.... They always ask that all the time. I don't always say yes, I need help, but that time it was just like everything was built up and I was kind of ashamed a little bit to ask for help, but then I was like, what the heck. I might as well just go ahead and ask. If they can help, then they can help.

This caregiver and many others shared their challenges only after reaching a point of crisis that encouraged them to seek help in that moment over others. Sara described feeling overwhelmed by the problems she was facing: "I was on the verge of getting evicted. I was behind on the bills. I had just lost my job and I was pregnant. So, it was a lot all at once." This distress and the desire to create a better future for her baby prompted her to finally ask her HCPs for support: "It was like, I have to do something. I can't sit here and do nothing.... So it was just like, then I'm about to bring another baby in the world and I can't bring her into a mess.... I had no choice."

Other participants were surprised at their own decision to share and felt like the questions simply caught them at a random moment of vulnerability. Echoing these sentiments, Charlotte contended that she was not necessarily sure what was different about the day she decided to share her struggles. However, she unexpectedly communicated her situation to her child's HCP when asked at that visit: "I'm very careful who I tell my story to, but it came so freely that day. I don't know what it was. I was crying and I don't even cry in front of people.... They just caught me in the time of venting, when you just can't hold it in anymore. I was just at that point." Even though they had all declined to do so multiple times in the past, these caregivers decided to talk about their social needs when asked yet again at these visits.

Most participants were glad they spoke up in these discussions as they then went on to have positive experiences working with the MLP lawyer and, in some cases, with their child's HCP. This basic but powerful belief that they had somewhere to turn helped lift some of the emotional burden many caregivers carried while navigating challenges alone. Nia described the comfort she took away from her conversations with the MLP lawyer: "Really just like you know letting me know, hey, we can take care of this, you know, you're not alone in this situation. Hey, there's resources. Hey, not only are there resources but listen, there's an ear." Knowledge that they had a point person to count on should they ever need to reach out fostered feelings of support among caregivers who previously felt lost, overwhelmed, or isolated. For example, Tiana's son has asthma exacerbated by poor housing quality. She spoke about a time that her son's HCP assisted with writing a letter of medical necessity. She emphasized how much it meant to her when the HCP took the extra step to reinforce that she was ready to help in any way she could: "It means a lot.... I had one place that needed a letter from a doctor stating that I am not allowed to be in any place with carpets.... And I had texted her and told her I'm in the midst

of moving again, but I need another letter. And she sent it to me. I have it in MyChart. She's like, 'if you need anything else, call me.... Let me know. I got you.'"

Perceptions of this commitment and support were potentially even more important to caregivers in the relationship than was the ability to fix the challenges at hand. Sequoia was most excited not at the expectation of automatic solutions but instead at the MLP lawyer's explicit assertion that she would be there to try: "I've never met anyone that actually told me – or reassured me – that they may not have all the answers for me, but they were connected to a lot of resources and this wasn't the end." Similarly, many caregivers did not necessarily expect that the HCP would be able to singlehandedly address their needs. Jessie appreciated that her child's HCP made an effort to connect her with resources even though they were not able to do anything personally: "My doctor couldn't help me but at least they were like, 'Oh, she can help you.'" Cultivation of these feelings of support did not require grand actions. Simple gestures often made a big difference in building trust and reassuring caregivers that they had someone on their team. When efforts could not make a difference in long-term resolution of needs, showing a desire to help in other ways still contributed to families feeling supported. One mother described the impact it had when the MLP lawyer thought to refer her family to a non-profit Christmas program: "[The program] actually showed up here on Christmas morning with food and gifts for me and my children. And they were able to have a Christmas that particular year, and it's something that they've never forgotten, and I've never forgotten." Caregivers perceived these small concrete steps as signs of commitment to family support.

Less tangible displays of care and interest over time also contributed to perceptions of authentic support within relationships. Even something as simple as body language and tone of voice made a big difference in trust to caregivers like Sherry: "She really was concerned. I heard

it in her voice. I seen it in her body language. She really was for him, and really wanted to do what was best for him.” Continuing to ask about the family’s well-being and reminding them of support made caregivers feel like the lawyer’s involvement was more than just a task to cross off her list. The MLP lawyer consistently checked in with Sara even when things were going well for her family. She was gratefully taken aback by the lawyer’s consistent care and concern: “Every time I went there [the clinic], she would ask me, ‘Everything all right? Is your house fine?’ She would really do that, would really ask.” Shonda shared that the lawyer still checks in on her son when she can to remind him that he will always have her support: “She makes it her business to let him know, I was here. I’m still here for you, kid. Even though things are going well, I am still here for you, because you never know. I’m here.”

Building partnership within the HCP-caregiver relationship was critical in further strengthening these feelings of genuine support. Many participants had never experienced this sense of alliance in an institutional setting. Checking in on caregivers’ feelings, opinions, and goals helped them feel truly seen and valued within interactions. Failing to elicit this input often alienated HCPs from the realities of caregivers’ lives and created distance within the relationship. In many cases, a lack of mutual engagement around potential solutions rendered HCP suggestions functionally useless. Marlana described past frustrations with an HCP who did not ask for her perspective: “It’s like for something that’s not an emergency it’s like, ‘okay, we’ll do this,’ and then the next time I see her, ‘you didn’t do that?’ It’s like, that’s not an emergency. If you see how many other things I have to do with all these kids, that’s not.” In addition to feeling judged that she did not pursue the suggestion, Marlana was exasperated that the HCP was so out of touch. She went on to discuss feeling like past providers did not think about the accessibility of their plans, neglecting the barriers that she might face along the way:

They had other resources they wanted you to reach out to in their other clinic, but their other clinic was more than a half hour away. If you take a bus, it's like double the time to get there. But you have to be able to get there. You have to pay out of pocket to get there and get back. And I have little ones. So, there's no daycare. So, if it wasn't really accessible, then it's not helping.

Perhaps because of experiences like Marlena's, caregivers deeply appreciated a collaborative approach. When the lawyer and HCPs sought feedback on plans, caregivers felt like they valued their thoughts as experts on the family. Participation in this process shifted the power dynamic to one in which caregivers had an equal seat at the table, something they were often denied. One mother described feeling like the MLP lawyer did not simply tell her what to do and move on. Instead, her opinion mattered in setting goals and making the plan: "She just took time to explain things to me, you know? She didn't just say, 'hey do this, do that, do this.' She said, 'hey, this is what we can do, what do you--?' And she took my input.... She established that, look, you have a voice, you know? That says a lot."

Positioning caregivers as leaders in their children's well-being also built self-efficacy by empowering them in their own efforts. Shonda shared that the MLP lawyer felt like a partner. The lawyer not only aided in resolving her needs but also equipped her with the knowledge and skills to independently advocate for her son: "She's not one of them ones that'll just walk in and take control. Everything she did, she sat and explained to me what she was doing, why she was doing it, what each section of the process meant, so that me as Mom, I could also be an advocate for my son." Several caregivers echoed that the supportive experience of working through problems enabled confidence in their personal abilities to pursue solutions. Sylvia reported developing skills that would allow her to tackle her problems more effectively should she ever

need to face them on her own: “I was like, well you can do that on your own now.” Another mother explained that she did not feel as overwhelmed after seeing firsthand that issue resolution is not an overnight process. She discussed her thoughts on facing similar problems in the future: “It wouldn’t be so unbearable and I felt like once I knew more about it I was able to actually digest it and dissect it more so that I will be able to understand, okay, listen, okay, this might be the situation now but there’s a process in the middle of it. It’s not just, you know, A-then-B.”

Another factor that facilitated partnership and trust within relationships was the consideration of the whole caregiver. Participants perceived that their relationships were more genuine when the lawyer or HCPs made the effort to know them as real people rather than as a sum of their struggles. When caregivers believed that their challenges would not singularly define perceptions of them, they became more comfortable. One mother shared that she appreciated when the lawyer pointed out her strengths, a display of confidence in her parental ability that she did not always receive from others. This practice also helped develop a rapport of trust: “If she feels like I’m doing something wrong, she’ll tell me, but for the most part she tells me I’m doing a good job.... So, it makes me feel good.... She don’t judge.” Another caregiver described that this feeling of being seen in her entirety is what made relationships with her child’s HCPs so special: “You’re not just a patient, you know, to some, you know? They understand you’re a person. They understand that you’re a parent. They understand that you’re somebody’s daughter and to me that means a lot.” Kylie had very negative perceptions of medical and legal institutions and was resistant to discussing her needs in these settings. However, she trusted this specific MLP lawyer as she felt the lawyer cared about her beyond just the tasks at hand: “She made me feel comfortable.... With her, you could say, ‘hey, I broke my foot today,’ and she’s concerned about stuff like that, you know what I’m saying?”

The establishment of relationships with caregivers surrounding social needs was not instantaneous. However, confidence and trust continued to develop when caregivers identified the relationship as a positive and reliable source of support. For example, Sequoia was initially anxious about sharing information. This hesitancy faded as the lawyer's actions repeatedly validated her trust: "But everything that I talked about with her, she always kept it confidential between us, unless it was something like, she needed to share – if someone was being harmed or something like that." For some caregivers, opening this line of communication required explicit reassurance. Sara was honest with the MLP lawyer about her fear that doctors would call DCF: "[The lawyer] was like, 'No, that's not what's going to happen.' She reassured me like a lot. That's why I'm more comfortable now like to ask for help from different resources."

As trust within the relationships strengthened, it worked to break down the fears and suspicions that previously prevented caregivers' full engagement in conversations around their challenges. In response, caregivers felt increasingly comfortable disclosing their struggles to the lawyer and to pediatric HCPs. Amy described this relational shift by outlining changes in her perceptions of her child's HCP: "I think it was kind of weird when we first met because, like I said, I was a little standoffish. I was like, Oh, my God. Here we go again. Someone else. What does she want? What does she want to know?... Once I'd seen that they were helping me—after that I completely felt so comfortable with [provider] I would tell her everything." This new emotional freedom even encouraged some caregivers to bring up their needs to others on their own. Kendra described working with the MLP lawyer on a later issue. She herself reached out to tell the lawyer about the situation now that she knew she could trust her: "Just because I feel comfortable talking to her, I brought it up, so I just told her the situation."



These foundational encounters shaped not only caregivers' perceptions of particular providers but also of the healthcare system more broadly. Many participants identified that this positive experience inspired a new propensity to engage with HCPs more generally about their needs. In this way, single relationships or experiences impacted the baseline trust and confidence that caregivers had in other HCPs or institutions moving forward. Some caregivers displayed this trust in an increased willingness to share with future providers. For example, Sara previously felt ashamed talking about her social needs. When asked how her interactions with HCPs have changed, she expressed that she is more likely to disclose what is going on in her life: "I fill them in a bit more with—I don't know, if they ask me, 'anything I need,' now I'd probably just be like—this recent time I was like, yeah, we're in a shelter. I opened up a bit more." This openness also reflects caregivers' strengthened hope and belief that they will not have to go through future hardships without support. Speaking about what she learned through her experiences working with the MLP lawyer and her child's HCPs, one mother described a transformation in how she thinks about asking for help in times of difficulties: "It made me realize that you can have more help. It's okay to ask for it. It's okay to be vulnerable to someone else that you don't know, don't trust.... It definitely changed my perspective of even if someone asked me if I need help that I would. If someone asked me, 'Are you okay?' It's okay to say no, I'm not."

## **Discussion**

### **The Value of Contextual Knowledge of the Caregiver Experience**

Throughout their narratives, caregivers recounted challenges ranging from issues with housing quality to barriers in the school system to trouble with utility bills and more. Many faced multiple needs concurrently, reflecting national data suggesting that this experience is not uncommon (Centers for Medicare & Medicaid Services, 2020). The pervasive nature of these

needs meant that caregivers were not dealing with the compartmentalized strain of a particular problem. Instead, stress was an inescapable force that drained them as they juggled the demands of competing priorities. Palakshappa et al. (2017) similarly reported this tension between conflicting demands as a source of stress in families experiencing food insecurity. These multiple needs also created a context in which the “little things” had outsized impact, as evidenced by Jasmine’s description of the strain her son’s medical appointments placed on their family.

Caregivers in general are at risk of exhaustion related to fear of not being a good enough parent (Hubert & Aujoulat, 2018). In this study, the burden of hardship only heightened this pressure and guilt. For Jessie, patching up their window every winter was a disappointing reminder that she was stuck in the same situation despite working so hard to achieve change. The results that these women were able to show for their efforts were rarely commensurate to the time and energy involved, and they often felt ignored by individuals like landlords in positions of power. Mounting stress and continuous moments of defeat contributed to feelings of shame, isolation, and desperation. They kept moving forward out of a desire to care for and protect their children, often pushing their own well-being aside to do so. Prior work surrounding the emotional impact of financial hardship on single mothers similarly found that caregivers were willing to sacrifice their own mental and physical well-being to provide for their children (Stack & Meredith, 2018).

The importance of examining these broader caregiver experiences of social needs is threefold. First, parental well-being directly impacts child development (Deater-Deckard & Panneton, 2017). Caregivers’ ability to maintain protective, buffering relationships is critical in healthy child development, especially in a situation of prolonged stress or adversity (Partap, 2019). It is much more difficult for mothers experiencing psychosocial barriers to successfully

take on this role (Condon & Sadler, 2019; Conn et al., 2020). For some caregivers, stress may eventually lead to maladaptive parenting behaviors (Masarik & Conger, 2017). As a result, general caregiver well-being and an understanding of the chronic stress they may be experiencing cannot be divorced from care of the child in the pediatric setting.

These narratives are also valuable because they can help uncover the lens through which some caregivers may construct their baseline thoughts, beliefs, and behaviors. Providers are often aware of the health impacts of SDOH but not necessarily of the ways that this context influences the caregiver experience of healthcare interactions. Although every family is different, knowledge of this framework can help providers better predict and understand how caregivers might perceive their words and actions. An exploration of these connections is woven throughout this discussion. Lastly, listening and reflecting on what caregivers go through in their navigation of social needs is vital in promoting empathy and respect among providers. These caregivers are resilient and tireless in their efforts to care for their families, and their strengths demand recognition.

### **Drivers of Distrust and Disengagement**

Many caregivers were hesitant to admit their struggles out of fear that their children's HCPs would think they could not care for their families, supporting similar findings in other research (Cullen et al., 2020; Knowles et al., 2018). This fear of misjudgment may partially stem from caregiver self-stigma and related shame. For example, Nia stated that "it looks like I can't take care of my children, but it's not that" before quickly emphasizing the factors that were out her control. This reflexive qualification seemed to respond to her own need to justify this perceived failure rather than to convince the interviewer. This supports previous research suggesting that shame may be a reflection of internalized social stigma (Keene et al., 2015) and

is often related to self-perception as a poor parent (Palakshappa et al., 2017). In these ways, judgment by HCPs following needs disclosure could represent a perceived confirmation of caregivers' own feelings of inadequacy.

Although caregiver anxiety stemmed partially from potential negative perception by an HCP, its greatest source was the possibility that the HCP could then act on that judgment. Specifically, caregivers worried about DCF intervention. Pediatric providers' proximity to child welfare systems as mandatory reporters created a dynamic in which caregivers perceived the HCP to hold some level of control over their family's future. Caregivers felt a lack of power within the relationship, reinforcing imbalances they felt in other settings. The few qualitative studies from the caregiver perspective consistently report this fear of consequences (Cullen et al., 2020; Knowles et al., 2018; Palakshappa et al., 2017; Schleifer, 2020). Some caregivers' fears extended into certainty that HCPs would take these actions, framing the HCP as an active adversary.

For some participants, this fear was driven by previous traumatic experiences interacting with DCF. This overarching fear cannot be separated from these personal histories nor from the underlying context of racialized inequities. DCF contact occurs at significantly higher rates among Black and Brown families (Sanmartin et al., 2020; Thomas et al., 2022). Up to half of Black children in the United States experience an investigation during their childhood (Kim et al., 2017). For caregivers of color like the women in this study, fears surrounding reports to DCF were not an unreasonable consideration but possibly an extension of broader historical mistrust in social and medical institutions (Jaiswal & Halkitis, 2019). Child Protective Services has recently developed the Family Assessment Response, an alternative track for low-risk cases that focuses on addressing underlying needs within families. Once a family's situation is determined

to be appropriate for this track, participation in services is voluntary. Although this model is promising, implementation has been heterogeneous across states (Kelly et al., 2020) and deep distrust is likely to remain a barrier. Advocacy must occur to strengthen these efforts and ensure that they meet their stated goals.

Fears of misjudgment and consequences ultimately precluded caregiver willingness to share their needs with HCPs. Other research similarly found that mothers worried about DCF involvement undertook strategies of “selective visibility” in their institutional interactions, picking and choosing what they shared to protect their vulnerability (Fong, 2019). Stigma may drive similar concealment as well (Keene et al., 2015). Some caregivers in the present study felt that HCPs prematurely established negative assumptions about them regardless of such strategies. This made caregivers skeptical of the motivations behind HCP questioning. For example, Amy interpreted inquiries about her social needs as an insulting sign that the HCP already suspected certain answers.

These perceived assumptions were frustrating, perhaps because they imparted the sense that HCPs did not care to see parents as anything other than their struggles. Given the extensive time and energy they put into supporting their families, these interactions may also have been received by caregivers as disrespectful. In previous work, Black mothers experiencing poverty discussed this scrutiny and perceived a similar institutional assumption that they were bad parents who deserve punishment rather than support (Elliott & Reid, 2019). Experiences like these put caregivers on the defensive and inspired reciprocal assumptions that the HCP could not be trusted. This both damaged the caregiver-HCP relationship and closed the door on meaningful engagement surrounding social needs. Other research supports that previous experiences of

healthcare discrimination or disrespect decrease caregiver comfort with screening (Byhoff et al., 2019; E. H. De Marchis et al., 2019) and damage the relationship (R. L. Sokol et al., 2021).

Although some caregivers discussed actively negative reactions from HCPs surrounding social needs, others described experiences of dismissal. Institutional figures like property owners consistently ignored caregivers in their efforts outside of the clinic setting. With this context in mind, HCP dismissal of caregiver concerns potentially upheld the notion that attempts to engage would be futile. Instead of wondering whether they should try again, wary caregivers may have left with the belief that experiences in the healthcare setting would be no different than elsewhere. In this way, a history of encounters outside of the clinic influenced the strength of this dismissal's impact on future engagement in healthcare. These experiences of disregard by HCPs may not be rare. Weiner et al. (2010) found that even when patients mentioned social factors central to their health, HCPs only probed more about half the time. Especially considering that these issues can be challenging to bring up in the first place, caregivers may perceive the failure to explore these topics further as a dismissal.

Underlying stigma consistently reinforced these negative beliefs and behaviors of avoidance, acting as a key barrier to caregiver engagement. Previous work in low-income adults suggests that the majority of stigma experiences in the healthcare setting arises from provider-patient exchanges rather than from personal shame (Allen et al., 2014). The role of caregiver and related judgment as a parent add an emotional complexity that likely heightens internalized stigma in the pediatric setting. However, caregivers' experiences in this study still seemed to reflect stigmatization from HCPs as a primary driver of perceptions and behaviors. Decreased caregiver desire to discuss social needs with pediatric HCPs (Zielinski et al., 2017), decreased health-seeking behaviors (Stack & Meredith, 2018), and unmet health needs (Allen et al., 2014)

are all associated with social stigma. Stigma, fear of misjudgment and consequences, past negative experiences, perceived assumptions, and feelings of dismissal all contributed to caregiver distrust of pediatric providers and disengagement in interactions surrounding social needs.

### **Promoting Experiences of Support**

First and foremost, HCPs must recognize the simple importance of asking these questions in their care for families. This is the initial step in potentially identifying opportunities for support. Only one mother in this study brought up her social needs to HCPs on her own, supporting research that many caregivers are unlikely to initiate asking for help (Colvin et al., 2016). After struggling with no heat in her home for two years, Fatima only received assistance with these utility challenges after an HCP asked about her needs. It is impossible to know how much longer she might have continued to face this challenge had no one asked her that day. Many other caregivers reported opening up at a point of desperation, exhaustion, or change that pushed them to seek help despite repeatedly declining to do so in the past. This variability in caregiver decisions surrounding when to share their needs points to the importance of intentional and consistent initiation of opportunities for them to do so. Caregivers with previous exposure to healthcare-based social needs screening may be more likely to ask for help (Colvin et al., 2016), possibly related to lower discomfort (E. H. De Marchis et al., 2019). This further supports the importance of normalizing these conversations across multiple visits. Although this study did not aim to analyze the nuances of screening tools themselves, further research in this area will help establish clear best practices in the pediatric setting (Morone, 2017).

As this study shows, these interactions hold high risk for emotional and relational harm if not carried out in ways that respect past experiences and center the caregiver perception of

support. Pediatric HCPs can learn from these narratives to more effectively and sensitively foster feelings of support among families experiencing hardship. Along with the existing literature, findings from this study informed the development of concepts that HCPs might consider in their practice moving forward. Although these suggestions specifically aim to address the context of interactions surrounding social needs, basic underlying themes may also apply to work supporting caregivers more generally.

Research from the provider perspective identifies the concern that questions about social needs may undermine trust (R. L. Sokol et al., 2021). The present study supports that these inquiries can indeed create discomfort, perpetuate stigma, and decrease trust. However, it also suggests that the driver of this tension is not necessarily the questions themselves but the surrounding context. Throughout caregiver narratives, negative perceptions did not stem from providers simply bringing up the topic of social needs. Instead, caregivers focused on fears associated with honesty, suspicions surrounding intentions, impressions of judgment, and more—how the interactions made them *feel*. As these factors reflect the underlying caregiver-provider relationship, they may be modifiable. The positive shift in opinion that occurred for many caregivers after building trust with their HCP supports this idea. Even Amy, who directly reported suspicion at these questions, later identified them as a source of support. This study thus supports previous findings that relationships with HCPs may be either facilitators or barriers to caregiver trust and engagement in work surrounding social needs (Byhoff et al., 2019; Cullen et al., 2020). With this framework comes the question of how providers can cultivate that shift in perception and help caregivers feel supported within these conversations. As a first step, providers can evaluate sources of discomfort and adjust their approach in direct response to these concerns.



As discussed, a history of personal or community involvement with DCF, instances of discrimination or disrespect, and other negative encounters like judgment or dismissal in the health care setting can shape the beliefs that caregivers bring into their interactions with subsequent HCPs. Awareness of the potential influence of these prior experiences is critical in conceptually approaching conversations surrounding social needs. Providers must appreciate and accept that even if they have not personally participated in these interactions, others may have in ways that lowered the threshold of baseline trust for all HCPs. Detailed knowledge of every individual's history is impossible. However, providers can draw from the principles of trauma-informed care to implement an approach that recognizes the possibility and likelihood of these experiences for all caregivers. Providers can then adapt their mindset and care to integrate universal awareness and respect for the impact these histories might have. This approach has been discussed elsewhere in the context of adverse childhood experiences (Racine et al., 2020).

In this study, some caregivers perceived inquiries about social needs as an underlying assumption about their capabilities as parents. To help avoid this feeling of targeted judgment, Palakshappa et al. (2017) and Schleifer et al. (2020) suggest emphasizing universality and explaining that all families are asked the same questions. By including an additional comment addressing the difficulty of knowing what families are going through, providers may further reinforce that these questions are not an assumption of need. Acknowledging the potential stress of experiences with social needs may help convey that the provider appreciates the complexity of the situation and its psychological impact, incorporating findings from previous work (Feder et al., 2006; Knowles et al., 2018). Although the spirit of the language is more important than the exact statement, one example may look like the following: "We ask everyone these same questions because it's impossible to know what families are going through just by looking at

them. We know that these challenges can impact health and create a lot of stress, and we want to make sure we aren't missing any opportunities to better support families.”

Throughout this study, caregivers repeatedly discussed their fears of DCF reports and the potential for consequences. Transparency around this subject is important to families in conversations around social needs (Schleifer, 2020). Directly acknowledging that this is something families may be thinking about can help reassure them of provider intentions. As mandated reporters, HCPs cannot make promises about the reporting process. However, they can briefly and explicitly outline concerns of safety or well-being that would trigger a report and reassure families that the goal of this information is to provide the best possible care and support for the child and family (Hamity et al., 2018). Little guidance currently exists on strategies for sensitive conversations about report processes in the healthcare setting. Development of functional tools in this area would assist HCPs in family-centered communication of this information. Future research should also further assess caregiver preferences surrounding language in social needs work (Magnan, 2021). Setting up conversations to foster feelings of support rather than of blame, judgment, or suspicion ultimately facilitates caregiver comfort and increases likelihood of meaningful engagement.

Language and conceptual approaches to conversations about social needs are important first steps that can open the door for caregiver involvement. However, building partnership within the relationship was key in this study to transforming that initial interaction into meaningful support over time. Elements of successful caregiver-provider partnership in the context of social needs have not been adequately explored in the literature. One critical facet of partnership in this study was elicitation of caregiver input. By asking caregivers their feelings, opinions, and goals, the MLP lawyer conveyed that she valued them as equal partners in the

thought process. This supports research on general patient-provider partnerships suggesting that incorporation of patients' experiential knowledge and their active involvement in care are important to establishing equal power dynamics (Ashcraft et al., 2019; Odero et al., 2020). This practice flipped the power dynamic that many caregivers were accustomed to experiencing in other settings. In the context of many participants' long histories of feeling ignored, devalued, and taken advantage of, the mutual nature of these exchanges became particularly impactful. Over time, this inclusion in their children's care also developed participants' belief in their own abilities to advocate for their families. Again, this newfound confidence was especially important given previous feelings of helplessness when working through these problems alone. In these ways, the simple practice of giving space and respect to caregivers' voices directly addressed some of the factors that defined past experiences.

This back-and-forth style of interaction was a behavior most frequently identified in relationships with the MLP lawyer. However, implementation of this interactive approach can be applied in the healthcare context as well. It may be particularly valuable in this setting considering prior work showing that pediatric HCPs tend to dominate communication in ways that disempower families (Giambra et al., 2018). In this study, continuous communication fostered caregiver belief that both partners were collaboratively working towards the same goal. Therefore, building towards this alliance may give HCPs an opportunity to reframe potentially adversarial perceptions of their role. This reinforces Ashcraft et al.'s (2019) finding that shared decision-making and goals are important to parental empowerment. Previous research on conversations in the pediatric setting suggests that HCPs may not provide adequate chances for parents to express their emotions or worries surrounding their child's well-being (Dicé et al.,

2020). Listening to and engaging with the caregiver perspective may combat this and allow for stronger emotional recognition and support.

When HCPs did not elicit the caregiver perspective, feelings of judgment often ensued. Confrontations with providers when caregivers failed to meet their expectations only further perpetuated their perception that HCPs viewed them negatively. At the same time, the disconnect between provider expectations and caregiver realities created a sense that the former was out of touch and unlikely to be an effective source of support. As Marlena described, lack of engagement surrounding potential plans ultimately rendered them ineffective. This supports research showing that information about social needs allows providers to shape and individualize clinical decisions around a family's situation (Tong et al., 2018). Weiner et al. (2010) uses the term "contextual error" to describe a plan whose effectiveness has been minimized after a failure to match its design to the social situation. In standardized visit scenarios, HCPs were almost 200% more likely to make these errors in encounters that were considered socially complicated versus those that were uncomplicated (Weiner et al., 2010). As a result, HCP efforts to engage more meaningfully with caregivers may not only encourage feelings of support and self-efficacy but also enable the delivery of accurate and effective care. This also suggests that screening practices surrounding social needs have inherent value to patient care outside of connection to resources alone.

Another factor that contributed to feelings of partnership among caregivers was small displays of care in interactions. These gestures signaled to caregivers that their family was more than simply a task on the to-do list. Such actions did not have to be significant in scope. Instead, their importance was in the perceived message of commitment and care of the family. For one mother, the fact that the MLP lawyer thought of her family for a local Christmas program meant

the world to her. While connection to this program could not solve the family's underlying needs, it may have communicated that the MLP lawyer cared about the children having positive Christmas memories and recognized how difficult that time might be for the caregiver.

Identifying and verbalizing caregivers' strengths also supported perceptions of real care within relationships by ensuring that caregivers felt seen for more than just their challenges. Employing a strengths-based approach may directly combat previously outlined fears and perceptions of negative HCP assumptions. Flacks and Boynton-Jarrett (2018) outline an example of this framework in application to social needs work. Reminding caregivers of their skills and recognizing that they are trying their best may also increase their confidence in themselves, working against potential internalized stigma and shame.

In this study, fostering the caregiver-provider relationship by building partnership ultimately built trust that allowed caregivers to feel more comfortable sharing honest details about their experiences. That this trust increased over time speaks to the importance of continuity of care with the same provider. Breaking through discomfort and fear of negative repercussions for relaying social risk created a freedom for caregivers to share what they were going through rather than selectively downplay it. This supports previous work suggesting that trust increases comfort with the screening process (E. H. De Marchis et al., 2019; Knowles et al., 2018). Over time, increased self-efficacy and trust may even empower caregivers to independently initiate conversations about social needs, as was the case with Kendra. The development of trusting relationships within families thus may have the power to transform care surrounding social needs from a solely formal screening process to an active, ongoing, and mutual conversation. This approach can partially mitigate worries that incorrect screening results may lead to misguided efforts to secure services or a failure to meet needs (Garg et al., 2018; Ray et al., 2020). In the

suggested framework, responses following a screening result would never occur in isolation from deeper engagement with the caregiver. Therefore, in the context of supportive relationships these potentially incorrect results and the appropriate response should be uncovered more easily.

This approach may also have the potential to help identify family issues early rather than at the point of crisis as was often the case for caregivers in this study. Many caregivers had never had this type of affirming, empowering relationship in the institutional setting. This newfound recognition of the possibility for these relationships to act as a source of support shifted caregiver perceptions moving forward. Although caregivers did not suddenly offer their trust freely and unconditionally, they did identify an increased propensity to actively engage rather than protectively close themselves off.

Providers' lack of confidence in their ability to address social needs is often a major barrier to their engagement (Kostelanetz et al., 2021; Palakshappa et al., 2017; Schickedanz et al., 2019; Tong et al., 2018). The emotional aspect of feeling unable to help also may contribute to provider burnout (E. De Marchis et al., 2019; Kostelanetz et al., 2021). However, this study suggested that caregivers do not necessarily expect their HCPs to have an all-encompassing knowledge or ability to resolve their needs. This finding reinforces other research in this area (Byhoff et al., 2019; Parry et al., 2021). Echoing the previous discussion of harm from screening questions, provider inability to fix problems did not damage the relationship so much as caregiver perceptions of judgment, assumptions, and disregard did. In this way, emotional support and partnership within relationships were valuable in and of themselves to caregivers. This highlights the critical nature of HCP engagement with caregivers surrounding social needs. This recognition of the unique importance of the HCP's role also pushes back against models suggesting tactics like universal provision of community resource sheets without screening or

individualized discussion (Garg et al., 2018; Ray et al., 2020). This is encouraging considering that genuine commitment and support are factors providers can continue to foster in their practice and in their relationships. This knowledge may decrease the pressure that dissuades some providers from engaging in these efforts.

At the same time, providers should take steps to increase their confidence and self-efficacy to maximize whatever tangible support may be available (E. De Marchis et al., 2019; Garg et al., 2019). This will look different in every setting depending on the resources at hand, and providers should familiarize themselves with community resources, referral options, and other available supports. If not already in existence, providers may work in collaboration with local social organizations to draft a resource list. Research supports that even if further services or referrals within the clinical setting are limited, maintaining up-to-date information on available community resources may be helpful to caregivers (E. H. De Marchis et al., 2020; Gottlieb et al., 2020). Further research might examine the relationships between community organizations and HCPs to strengthen these connections in the future (Beck et al., 2018). Additional work should also continue to explore the comparative effectiveness of clinic-based social needs interventions.

### **Policy Implications**

This study's exploration of caregiver experiences of support within the pediatric setting points to larger opportunities for change within clinical practice. Integrating this work into medical training may be a feasible first step in breaking down some of the identified barriers to trust. These efforts should go beyond didactic modules to incorporate functional tools and practice opportunities that can increase provider self-efficacy and confidence in taking a trauma-informed, strengths-based approach to SDOH work. Deeper training in the emotional nuances of

this work will be especially important in decreasing caregiver experiences of stigma within the healthcare setting. This training should extend to other clinic staff like front desk employees to further reduce the likelihood of stigmatizing interactions. Pushing for increased institutional capacity for HCPs to carry out work surrounding social needs will be critical moving forward in supporting feasibility and sustainability (Kostelanetz et al., 2021; Schickedanz et al., 2019). For example, SDOH ICD-10 standardization in electronic medical record documentation can support the development of reimbursement models for social needs work in the clinic setting (Olson et al., 2019). Further clarifying the overlap between efforts in the fields of SDOH and adverse childhood experiences (ACEs) will also aid in strengthening progress toward mutual goals (Magnan, 2021).

HCP involvement is only one piece of the puzzle. The study's context of an MLP program also underscores the importance of interdisciplinary approaches to social needs work. Financial and institutional support for cross-sector collaboration will maximize differing professional strengths and more effectively address patient needs. Less than half of hospitals and health systems nationally report functional partnerships with community-based social needs providers (Lee & Korba, 2017), suggesting a need for strengthened formal cross-sector partnerships (Kreuter et al., 2021). Given the described disparities in DCF involvement, these sectors must also strive collaboratively to develop accountability frameworks for reporting processes. Lastly, efforts at the individual and community level are not enough. Providers should actively involve themselves in advocacy surrounding both the bolstering of government assistance programs and the passage of policies that affect underlying SDOH inequities like institutional racism, income inequality, and housing instability.



## **Limitations**

This study should be interpreted in light of its limitations. Caregivers who agreed to participate in this study may have been willing to do so because of positive experiences with the MLP. By extension, they may also have more positive perceptions of and relationships with their children's HCPs. However, this study did not aim to determine perceptions of the MLP and instead to contribute to general thematic knowledge surrounding caregiver experiences of social needs and HCP interactions. To be connected to the MLP, caregivers had to disclose their social situations at some point in time. As a result, this study sample inherently excluded caregivers who did not share their needs in the healthcare setting and who may have the highest levels of distrust. Furthermore, all participants received some level of intervention within the MLP that they may associate with their HCP.

Broader interactions with and perceptions of health providers and the healthcare system may be influenced by the characteristics of the MLP in this study and the personal attributes of the lawyer. For example, positive perceptions of the lawyer may have then transferred to the HCP. Further research on the impact of these cross-sector caregiver relationships on broader institutional perceptions will be valuable. Furthermore, the MLP provided training to HCPs surrounding health-harming legal needs. This may have affected the way that providers approached SDOH during these experiences. It is impossible to know the extent to which this receipt of services or the specific design of the intervention contributed to perceptions, and conclusions may not be transferrable to all settings. However, this study did not hope to paint a single all-inclusive portrait of caregiver narrative. Instead, it aimed to identify contextual factors that might differentially impact how caregivers approach and perceive interactions with their

children's HCPs. In response, the study then pushes HCPs to adopt practices in which consideration of these nuances is central to their work surrounding social needs.

### **Conclusion**

Our study identifies multiple ways that the caregiver experience of navigating social needs influences perceptions of and interactions with their children's health care providers. Primary drivers of distrust and disengagement included stigma, fear of misjudgment and consequences, past negative experiences, perceived assumptions, and feelings of dismissal. Understanding of these factors can inform practice as pediatric providers can adapt their approaches to social needs in ways that directly respond to these barriers. In doing so, relationships between providers and caregivers can reflect genuine partnership and foster meaningful experiences of support. These positive experiences may have the potential to shape perceptions of health care providers and systems more broadly. Further work is needed to develop practical tools that support these efforts and to strengthen broad support services at the community and systemic levels.

## References

- Abrams, E. M., Greenhawt, M., Shaker, M., Pinto, A. D., Sinha, I., & Singer, A. (2022). The COVID-19 pandemic: Adverse effects on the social determinants of health in children and families. *Annals of Allergy, Asthma & Immunology*, *128*(1), 19–25. <https://doi.org/10.1016/j.anai.2021.10.022>
- Alamilla, S. G., & Cano, M. Á. (2022). COVID-19 and adverse social determinants of health. *Behavioral Medicine*, *48*(2), 67–71. <https://doi.org/10.1080/08964289.2022.2027859>
- Allen, H., Wright, B. J., Harding, K., & Broffman, L. (2014). The role of stigma in access to health care for the poor. *The Milbank Quarterly*, *92*(2), 289–318. <https://doi.org/10.1111/1468-0009.12059>
- Alley, D. E., Ashford, N. C., & Gavin, A. M. (2019). Payment innovations to drive improvements in pediatric care: The integrated Care for Kids model. *JAMA Pediatrics*, *173*(8), 717–718. <https://doi.org/10.1001/jamapediatrics.2019.1703>
- Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., & Ray, K. N. (2019). Parent empowerment in pediatric healthcare settings: A systematic review of observational studies. *The Patient - Patient-Centered Outcomes Research*, *12*(2), 199–212. <https://doi.org/10.1007/s40271-018-0336-2>
- Barnidge, E., Krupsky, K., LaBarge, G., & Arthur, J. (2020). Food insecurity screening in pediatric clinical settings: A caregivers' perspective. *Maternal and Child Health Journal*, *24*(1), 101–109. <https://doi.org/10.1007/s10995-019-02785-6>
- Barnidge, E., LaBarge, G., Krupsky, K., & Arthur, J. (2017). Screening for food insecurity in pediatric clinical settings: Opportunities and barriers. *Journal of Community Health*, *42*(1), 51–57. <https://doi.org/10.1007/s10900-016-0229-z>

- Beck, A. F., Cohen, A. J., Colvin, J. D., Fichtenberg, C. M., Fleegler, E. W., Garg, A., Gottlieb, L. M., Pantell, M. S., Sandel, M. T., Schickedanz, A., & Kahn, R. S. (2018). Perspectives from the Society for Pediatric Research: Interventions targeting social needs in pediatric clinical care. *Pediatric Research*, *84*(1), 10–21. <https://doi.org/10.1038/s41390-018-0012-1>
- Bennett, R. A., & LeBaron, V. T. (2019). Parental perspectives on roles in end-of-life decision making in the pediatric intensive care unit: An integrative review. *Journal of Pediatric Nursing*, *46*, 18–25. <https://doi.org/10.1016/j.pedn.2019.02.029>
- Body, D., Landau, R., Reyes, E., & Reina, V. (2021). *Current responses to housing insecurity: A focus on vulnerable residential renters and landlords*. Federal Reserve Bank of New York. [https://www.newyorkfed.org/medialibrary/media/newsevents/news/regional\\_outreach/2021/housing-insecurity](https://www.newyorkfed.org/medialibrary/media/newsevents/news/regional_outreach/2021/housing-insecurity)
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2018). Parents’ voices: “Our process of advocating for our child with autism.” A meta-synthesis of parents’ perspectives. *Child: Care, Health and Development*, *44*(1), 147–160. <https://doi.org/10.1111/cch.12504>
- Bright Futures. (2019). *Integrating social determinants of health into health supervision visits*. American Academy of Pediatrics. [https://brightfutures.aap.org/Bright%20Futures%20Documents/BF\\_IntegrateSDoH\\_Tipsheet.pdf](https://brightfutures.aap.org/Bright%20Futures%20Documents/BF_IntegrateSDoH_Tipsheet.pdf)
- Bright Futures. (2021). *Recommendations for preventive pediatric health care*. American Academy of Pediatrics. [https://downloads.aap.org/AAP/PDF/periodicity\\_schedule.pdf](https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf)

- Butler, A. E., Hall, H., & Copnell, B. (2018). Becoming a team: The nature of the parent-healthcare provider relationship when a child is dying in the pediatric intensive care unit. *Journal of Pediatric Nursing, 40*, e26–e32. <https://doi.org/10.1016/j.pedn.2018.02.002>
- Byhoff, E., De Marchis, E. H., Hessler, D., Fichtenberg, C., Adler, N., Cohen, A. J., Doran, K. M., Ettinger de Cuba, S., Fleegler, E. W., Gavin, N., Huebschmann, A. G., Lindau, S. T., Tung, E. L., Raven, M., Jepson, S., Johnson, W., Olson, A. L., Sandel, M., Sheward, R. S., & Gottlieb, L. M. (2019). Part II: A qualitative study of social risk screening acceptability in patients and caregivers. *American Journal of Preventive Medicine, 57*(6, Supplement 1), S38–S46. <https://doi.org/10.1016/j.amepre.2019.07.016>
- Centers for Medicare & Medicaid Services. (2020). *Accountable Health Communities (AHC) model evaluation: First evaluation report*. <https://innovation.cms.gov/data-and-reports/2020/ahc-first-eval-rpt>
- Coley, R. L., Leventhal, T., Lynch, A. D., & Kull, M. (2013). Relations between housing characteristics and the well-being of low-income children and adolescents. *Developmental Psychology, 49*(9), 1775–1789. <https://doi.org/10.1037/a0031033>
- Colvin, J. D., Bettenhausen, J. L., Anderson-Carpenter, K. D., Collie-Akers, V., & Chung, P. J. (2016). Caregiver opinion of in-hospital screening for unmet social needs by pediatric residents. *Academic Pediatrics, 16*(2), 161–167. <https://doi.org/10.1016/j.acap.2015.06.002>
- Condon, E. M., & Sadler, L. S. (2019). Toxic stress and vulnerable mothers: A multilevel framework of stressors and strengths. *Western Journal of Nursing Research, 41*(6), 872–900. <https://doi.org/10.1177/0193945918788676>

- Conn, A.-M., Szilagyi, M., & Forkey, H. (2020). Adverse childhood experience and social risk: Pediatric practice and potential. *Academic Pediatrics*, *20*(5), 573–574. <https://doi.org/10.1016/j.acap.2020.03.013>
- Conroy, K., Samnaliev, M., Cheek, S., & Chien, A. T. (2021). Pediatric Primary Care-Based Social Needs Services and Health Care Utilization. *Academic Pediatrics*, *21*(8), 1331–1337. <https://doi.org/10.1016/j.acap.2021.01.012>
- Council on Community Pediatrics. (2016). Poverty and child health in the United States. *Pediatrics*, *137*(4), e20160339. <https://doi.org/10.1542/peds.2016-0339>
- Cullen, D., Attridge, M., & Fein, J. A. (2020). Food for thought: A qualitative evaluation of caregiver preferences for food insecurity screening and resource referral. *Academic Pediatrics*, *20*(8), 1157–1162. <https://doi.org/10.1016/j.acap.2020.04.006>
- Cullen, D., Wilson-Hall, L., McPeak, K., & Fein, J. (2022). Pediatric Social Risk Screening: Leveraging Research to Ensure Equity. *Academic Pediatrics*, *22*(2), 190–192. <https://doi.org/10.1016/j.acap.2021.09.013>
- De Marchis, E. H., Alderwick, H., & Gottlieb, L. M. (2020). Do patients want help addressing social risks? *Journal of the American Board of Family Medicine: JABFM*, *33*(2), 170–175. <https://doi.org/10.3122/jabfm.2020.02.190309>
- De Marchis, E. H., Hessler, D., Fichtenberg, C., Adler, N., Byhoff, E., Cohen, A. J., Doran, K. M., Ettinger de Cuba, S., Fleegler, E. W., Lewis, C. C., Lindau, S. T., Tung, E. L., Huebschmann, A. G., Prather, A. A., Raven, M., Gavin, N., Jepson, S., Johnson, W., Ochoa, E., ... Gottlieb, L. M. (2019). Part I: A quantitative study of social risk screening acceptability in patients and caregivers. *American Journal of Preventive Medicine*, *57*(6, Supplement 1), S25–S37. <https://doi.org/10.1016/j.amepre.2019.07.010>

- De Marchis, E., Knox, M., Hessler, D., Willard-Grace, R., Olayiwola, J. N., Peterson, L. E., Grumbach, K., & Gottlieb, L. M. (2019). Physician burnout and higher clinic capacity to address patients' social needs. *Journal of the American Board of Family Medicine: JABFM*, 32(1), 69–78. <https://doi.org/10.3122/jabfm.2019.01.180104>
- Deater-Deckard, K., & Panneton, R. (2017). Consequences of parenting stress for children. In *Parental Stress and Early Child Development: Adaptive and Maladaptive Outcomes*. Springer International Publishing.
- Dicé, F., Dolce, P., Maiello, A., & Freda, M. F. (2020). Exploring emotions in dialog between health provider, parent and child. An observational study in pediatric primary care. *Pratiques Psychologiques*, 26(1), 69–84. <https://doi.org/10.1016/j.prps.2018.12.001>
- Drennen, C. R., Coleman, S. M., Cuba, S. E. de, Frank, D. A., Chilton, M., Cook, J. T., Cutts, D. B., Heeren, T., Casey, P. H., & Black, M. M. (2019). Food Insecurity, Health, and Development in Children Under Age Four Years. *Pediatrics*, 144(4). <https://doi.org/10.1542/peds.2019-0824>
- Dwomoh, I., & Dinolfo, E. A. (2018). Effects of homelessness on children. *Pediatrics In Review*, 39(10), 530–532. <https://doi.org/10.1542/pir.2018-0047>
- Elliott, S., & Reid, M. (2019). Low-income black mothers parenting adolescents in the mass incarceration era: The long reach of criminalization. *American Sociological Review*, 84(2), 197–219. <https://doi.org/10.1177/0003122419833386>
- Feder, G. S., Hutson, M., Ramsay, J., & Taket, A. R. (2006). Women Exposed to Intimate Partner Violence: Expectations and Experiences When They Encounter Health Care Professionals: A Meta-analysis of Qualitative Studies. *Archives of Internal Medicine*, 166(1), 22–37. <https://doi.org/10.1001/archinte.166.1.22>

- Flacks, J., & Boynton-Jarrett, R. (2018). *A strengths-based approach to screening families for health-related social needs*. Center for the Study of Social Policy. <https://www.careinnovations.org/wp-content/uploads/2018-A-strengths-based-approach-to-screening.pdf>
- Fong, K. (2019). Concealment and Constraint: Child Protective Services Fears and Poor Mothers' Institutional Engagement. *Social Forces*, 97(4), 1785–1810. <https://doi.org/10.1093/sf/soy093>
- Fraze, T. K., Brewster, A. L., Lewis, V. A., Beidler, L. B., Murray, G. F., & Colla, C. H. (2019). Prevalence of screening for food insecurity, housing instability, utility needs, transportation needs, and interpersonal violence by US physician practices and hospitals. *JAMA Network Open*, 2(9), e1911514. <https://doi.org/10.1001/jamanetworkopen.2019.11514>
- Garg, A., Cull, W., Olson, L., Boyd, A. F., Federico, S. G., Dreyer, B., & Racine, A. D. (2019). Screening and referral for low-income families' social determinants of health by US pediatricians. *Academic Pediatrics*, 19(8), 875–883. <https://doi.org/10.1016/j.acap.2019.05.125>
- Garg, A., Sheldrick, R. C., & Dworkin, P. H. (2018). The inherent fallibility of validated screening tools for social determinants of health. *Academic Pediatrics*, 18(2), 123–124. <https://doi.org/10.1016/j.acap.2017.12.006>
- Garg, A., Toy, S., Tripodis, Y., Silverstein, M., & Freeman, E. (2015). Addressing social determinants of health at well child care visits: A cluster rct. *Pediatrics*, 135(2), e296–e304. <https://doi.org/10.1542/peds.2014-2888>



- Giambra, B. K., Haas, S. M., Britto, M. T., & Lipstein, E. A. (2018). Exploration of parent–provider communication during clinic visits for children with chronic conditions. *Journal of Pediatric Health Care*, 32(1), 21–28. <https://doi.org/10.1016/j.pedhc.2017.06.005>
- Gottlieb, L. M., Adler, N. E., Wing, H., Velazquez, D., Keeton, V., Romero, A., Hernandez, M., Munoz Vera, A., Urrutia Caceres, E., Arevalo, C., Herrera, P., Bernal Suarez, M., & Hessler, D. (2020). Effects of in-person assistance vs personalized written resources about social services on household social risks and child and caregiver health: A randomized clinical trial. *JAMA Network Open*, 3(3), e200701. <https://doi.org/10.1001/jamanetworkopen.2020.0701>
- Gottlieb, L. M., Hessler, D., Long, D., Laves, E., Burns, A. R., Amaya, A., Sweeney, P., Schudel, C., & Adler, N. E. (2016). Effects of social needs screening and in-person service navigation on child health: A randomized clinical trial. *JAMA Pediatrics*, 170(11), e162521. <https://doi.org/10.1001/jamapediatrics.2016.2521>
- Gottlieb, L. M., Wing, H., & Adler, N. E. (2017). A systematic review of interventions on patients’ social and economic needs. *American Journal of Preventive Medicine*, 53(5), 719–729. <https://doi.org/10.1016/j.amepre.2017.05.011>
- Hake, M., Dewey, A., Engelhard, E., Strayer, M., Dawes, S., & Summerfelt, T. (2021). *The impact of the coronavirus on food insecurity in 2020 & 2021*. Feeding America. <https://www.feedingamerica.org/research/coronavirus-hunger-research>
- Hamity, C., Jackson, A., Peralta, L., & Bellows, J. (2018). Perceptions and experience of patients, staff, and clinicians with social needs assessment. *The Permanente Journal*, 22, 18–105. <https://doi.org/10.7812/TPP/18-105>

- Henrikson, N. B., Blasi, P. R., Dorsey, C. N., Mettert, K. D., Nguyen, M. B., Walsh-Bailey, C., Macuiba, J., Gottlieb, L. M., & Lewis, C. C. (2019). Psychometric and Pragmatic Properties of Social Risk Screening Tools: A Systematic Review. *American Journal of Preventive Medicine*, *57*(6, Supplement 1), S13–S24. <https://doi.org/10.1016/j.amepre.2019.07.012>
- Hubert, S., & Aujoulat, I. (2018). Parental burnout: When exhausted mothers open up. *Frontiers in Psychology*, *9*. <https://www.frontiersin.org/article/10.3389/fpsyg.2018.01021>
- Jaiswal, J., & Halkitis, P. N. (2019). Towards a more inclusive and dynamic understanding of medical mistrust informed by science. *Behavioral Medicine*, *45*(2), 79–85. <https://doi.org/10.1080/08964289.2019.1619511>
- Keene, D. E., Cowan, S. K., & Baker, A. C. (2015). “When you’re in a crisis like that, you don’t want people to know”: Mortgage strain, stigma, and mental health. *American Journal of Public Health*, *105*(5), 1008–1012. <https://doi.org/10.2105/AJPH.2014.302400>
- Keene, D. E., Murillo, S., Benfer, E. A., Rosenthal, A., & Fenick, A. M. (2020). Reducing the justice gap and improving health through medical-legal partnerships. *The Journal of Legal Medicine*, *40*(2), 229–245. <https://doi.org/10.1080/01947648.2020.1816233>
- Kelly, C., Street, C., & Building, M. E. S. (2020). Child maltreatment 2020. *Child Maltreatment*, 313.
- Kim, H., Wildeman, C., Jonson-Reid, M., & Drake, B. (2017). Lifetime prevalence of investigating child maltreatment among US children. *American Journal of Public Health*, *107*(2), 274–280. <https://doi.org/10.2105/AJPH.2016.303545>
- Knowles, M., Khan, S., Palakshappa, D., Cahill, R., Kruger, E., Poserina, B. G., Koch, B., & Chilton, M. (2018). Successes, challenges, and considerations for integrating referral into

- food insecurity screening in pediatric settings. *Journal of Health Care for the Poor and Underserved*, 29(1), 181–191. <https://doi.org/10.1353/hpu.2018.0012>
- Kostelanetz, S., Pettapiece-Phillips, M., Weems, J., Spalding, T., Roumie, C., Wilkins, C. H., & Kripalani, S. (2021). Health care professionals' perspectives on universal screening of social determinants of health: A mixed-methods study. *Population Health Management*. <https://doi.org/10.1089/pop.2021.0176>
- Kreuter, M. W., Thompson, T., McQueen, A., & Garg, R. (2021). *Addressing social needs in health care settings: Evidence, challenges, and opportunities for public health* (SSRN Scholarly Paper No. 3865973). Social Science Research Network. <https://doi.org/10.1146/annurev-publhealth-090419-102204>
- Larson, K., Russ, S. A., Crall, J. J., & Halfon, N. (2008). Influence of multiple social risks on children's health. *Pediatrics*, 121(2), 337–344. <https://doi.org/10.1542/peds.2007-0447>
- Leddy, A. M., Weiser, S. D., Palar, K., & Seligman, H. (2020). A conceptual model for understanding the rapid COVID-19–related increase in food insecurity and its impact on health and healthcare. *The American Journal of Clinical Nutrition*, 112(5), 1162–1169. <https://doi.org/10.1093/ajcn/nqaa226>
- Lee, J., & Korba, C. (2017). *Social determinants of health: How are hospitals and health systems investing in and addressing social needs?* Deloitte. <https://www2.deloitte.com/content/dam/Deloitte/us/Documents/life-sciences-health-care/us-lshc-addressing-social-determinants-of-health.pdf>
- Lin, J. L., Clark, C. L., Halpern-Felsher, B., Bennett, P. N., Assis-Hassid, S., Amir, O., Nunez, Y. C., Cleary, N. M., Gehrman, S., Grosz, B. J., & Sanders, L. M. (2020). Parent

- perspectives in shared decision-making for children with medical complexity. *Academic Pediatrics*, 20(8), 1101–1108. <https://doi.org/10.1016/j.acap.2020.06.008>
- Magnan, S. (2021). Social determinants of health 201 for health care: Plan, Do, Study, Act. *NAM Perspectives*, 2021, 10.31478/202106c. <https://doi.org/10.31478/202106c>
- Masarik, A. S., & Conger, R. D. (2017). Stress and child development: A review of the Family Stress Model. *Current Opinion in Psychology*, 13, 85–90. <https://doi.org/10.1016/j.copsy.2016.05.008>
- Melzer, S. M. (2022). Addressing social determinants of health in pediatric health systems: Balancing mission and financial sustainability. *Current Opinion in Pediatrics*, 34(1), 8–13. <https://doi.org/10.1097/MOP.0000000000001083>
- Morone, J. (2017). An integrative review of social determinants of health assessment and screening tools used in pediatrics. *Journal of Pediatric Nursing*, 37, 22–28. <https://doi.org/10.1016/j.pedn.2017.08.022>
- Odero, A., Pongy, M., Chauvel, L., Voz, B., Spitz, E., Pétré, B., & Baumann, M. (2020). Core values that influence the patient—healthcare professional power dynamic: Steering interaction towards partnership. *International Journal of Environmental Research and Public Health*, 17(22), 8458. <https://doi.org/10.3390/ijerph17228458>
- Oldfield, B. J., Casey, M., DeCew, A., Morales, S. I., & Olson, D. P. (2021). Screening for social determinants of health among children: Patients’ preferences for receiving information to meet social needs and a comparison of screening instruments. *Population Health Management*, 24(1), 141–148. <https://doi.org/10.1089/pop.2019.0211>
- Olson, D. P., Oldfield, B. J., & Morales, S. I. (2019). *Standardizing social determinants of health assessments*. <https://www.healthaffairs.org/doi/10.1377/forefront.20190311.823116/full/>

- Palakshappa, D., Douppnik, S., Vasani, A., Khan, S., Seifu, L., Feudtner, C., & Fiks, A. G. (2017). Suburban families' experience with food insecurity screening in primary care practices. *Pediatrics*, *140*(1), e20170320. <https://doi.org/10.1542/peds.2017-0320>
- Parolin, Z., Sophie Collyer, & Megan A. Curran. (2022). *Absence of monthly child tax credit leads to 3.7 million more children in poverty in January 2022*. [www.povertycenter.columbia.edu/publication/monthly-poverty-january-2022](http://www.povertycenter.columbia.edu/publication/monthly-poverty-january-2022)
- Parry, J., Vanstone, M., Grignon, M., & Dunn, J. R. (2021). Primary care-based interventions to address the financial needs of patients experiencing poverty: A scoping review of the literature. *International Journal for Equity in Health*, *20*, 219. <https://doi.org/10.1186/s12939-021-01546-8>
- Partap, A. (2019). New approach to pediatric treatment planning to support caregivers living with adversities. *Pediatric Annals*, *48*(7), e262–e268. <https://doi.org/10.3928/19382359-20190612-01>
- Peltz, A., & Garg, A. (2019). Food Insecurity and Health Care Use. *Pediatrics*, *144*(4), e20190347. <https://doi.org/10.1542/peds.2019-0347>
- Racine, N., Killam, T., & Madigan, S. (2020). Trauma-informed care as a universal precaution: Beyond the Adverse Childhood Experiences Questionnaire. *JAMA Pediatrics*, *174*(1), 5–6. <https://doi.org/10.1001/jamapediatrics.2019.3866>
- Ray, K. N., Gitz, K. M., Hu, A., Davis, A. A., & Miller, E. (2020). Nonresponse to health-related social needs screening questions. *Pediatrics*, *146*(3). <https://doi.org/10.1542/peds.2020-0174>
- Sanmartin, M. X., Ali, M. M., Lynch, S., & Aktas, A. (2020). Association between state-level criminal justice-focused prenatal substance use policies in the US and substance use-

- related foster care admissions and family reunification. *JAMA Pediatrics*, 174(8), 782–788. <https://doi.org/10.1001/jamapediatrics.2020.1027>
- Schickedanz, A., Hamity, C., Rogers, A., Sharp, A. L., & Jackson, A. (2019). Clinician experiences and attitudes regarding screening for social determinants of health in a large integrated health system. *Medical Care*, 57 Suppl 6 Suppl 2, S197–S201. <https://doi.org/10.1097/MLR.0000000000001051>
- Schleifer, D. (2020). It's about trust: Low-income parents' perspectives on how pediatricians can screen for social determinants of health. *Health Services Research*, 55(S1), 134–135. <https://doi.org/10.1111/1475-6773.13524>
- Shrider, E., Kollar, M., Chen, F., Semega, J., & U.S. Census Bureau. (2021). *Income and poverty in the United States: 2020* (pp. 60–273). U.S. Government Publishing Office.
- Smith, L. A., Bokhour, B., Hohman, K. H., Miroshnik, I., Kleinman, K. P., Cohn, E., Cortés, D. E., Galbraith, A., Rand, C., & Lieu, T. A. (2008). Modifiable risk factors for suboptimal control and controller medication underuse among children with asthma. *Pediatrics*, 122(4), 760–769. <https://doi.org/10.1542/peds.2007-2750>
- Sokol, R., Austin, A., Chandler, C., Byrum, E., Bousquette, J., Lancaster, C., Doss, G., Dotson, A., Urbaeva, V., Singichetti, B., Brevard, K., Wright, S. T., Lanier, P., & Shanahan, M. (2019). Screening children for social determinants of health: A systematic review. *Pediatrics*, 144(4), e20191622. <https://doi.org/10.1542/peds.2019-1622>
- Sokol, R. L., Ammer, J., Stein, S. F., Trout, P., Mohammed, L., & Miller, A. L. (2021). Provider perspectives on screening for social determinants of health in pediatric settings: A qualitative study. *Journal of Pediatric Health Care*, 35(6), 577–586. <https://doi.org/10.1016/j.pedhc.2021.08.004>

- Stack, R. J., & Meredith, A. (2018). The impact of financial hardship on single parents: An exploration of the journey from social distress to seeking help. *Journal of Family and Economic Issues*, 39(2), 233–242. <https://doi.org/10.1007/s10834-017-9551-6>
- Taylor, L. A., Tan, A. X., Coyle, C. E., Ndumele, C., Rogan, E., Canavan, M., Curry, L. A., & Bradley, E. H. (2016). Leveraging the social determinants of health: What works? *PLoS ONE*, 11(8), e0160217. <https://doi.org/10.1371/journal.pone.0160217>
- Thomas, M. M. C., Miller, D. P., & Morrissey, T. W. (2019). Food Insecurity and Child Health. *Pediatrics*, 144(4), e20190397. <https://doi.org/10.1542/peds.2019-0397>
- Thomas, M. M. C., Waldfogel, J., & Williams, O. F. (2022). Inequities in Child Protective Services contact between Black and White children. *Child Maltreatment*, 10775595211070248. <https://doi.org/10.1177/10775595211070248>
- Tong, S. T., Liaw, W. R., Kashiri, P. L., Pecsok, J., Rozman, J., Bazemore, A. W., & Krist, A. H. (2018). Clinician experiences with screening for social needs in primary care. *The Journal of the American Board of Family Medicine*, 31(3), 351–363. <https://doi.org/10.3122/jabfm.2018.03.170419>
- United States Census Bureau. (2022). *Week 44 Household Pulse Survey: March 30-April 11*. Census.Gov. <https://www.census.gov/data/tables/2022/demo/hhp/hhp44.html>
- Weiner, S. J., Schwartz, A., Weaver, F., Goldberg, J., Yudkowsky, R., Sharma, G., Binns-Calvey, A., Preyss, B., M. Schapira, M., Persell, S. D., Jacobs, E., & Abrams, R. I. (2010). Contextual errors and failures in individualizing patient care. *Annals of Internal Medicine*, 153(2), 69–75. <https://doi.org/10.7326/0003-4819-153-2-201007200-00002>

Wolfson, J. A., & Leung, C. W. (2020). Food Insecurity During COVID-19: An Acute Crisis With Long-Term Health Implications. *American Journal of Public Health, 110*(12), 1763–1765. <https://doi.org/10.2105/AJPH.2020.305953>

World Health Organization. (2022). *Social determinants of health*. <https://www.who.int/health-topics/social-determinants-of-health>

Zielinski, S., Paradis, H. A., Herendeen, P., & Barbel, P. (2017). The identification of psychosocial risk factors associated with child neglect using the WE-CARE screening tool in a high-risk population. *Journal of Pediatric Health Care, 31*(4), 470–475. <https://doi.org/10.1016/j.pedhc.2016.12.005>