

# IT'S ABOUT TRUST

## Low-Income Parents' Perspectives on How Pediatricians Can Screen for Social Determinants of Health

JUNE 2019





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## FOREWORD FROM UNITED HOSPITAL FUND

The following report contains important findings from focus group research on parent perspectives on social needs screening interventions that occur during pediatric primary care visits. The United Hospital Fund commissioned this report as a result of growing efforts (including our own) to encourage child health providers to begin universally screening parents of young children for unmet social needs that can affect early childhood health and development.

Clinical efforts to address “social determinants of health” have increased for good reason. Decades of research have shown that, just as individual behavior, genetics and medical care are important influencers of health, so, too, are the social conditions under which individuals live, work, play and learn. These nonmedical contributors to health outcomes include, but are not limited to, access to healthful food, high-quality child care and safe housing. Consensus is rapidly growing in the medical community that addressing the nonmedical factors that contribute to ill health is essential to improving population health, ending health disparities and reducing health care costs.

Addressing social determinants of health in childhood is particularly important. Children in the United States are more likely than any other age group to live in poverty. Nearly half of all families are in financial distress, with many lacking access to essential needs like food, child care and housing. The strain of poverty can also make it harder for parents to provide the routine nurturing interactions with their children that fuel brain development

and protect against toxic stress. Unmet social needs in early childhood can have long-lasting and wide-ranging consequences, including increased risk for chronic health conditions, behavioral problems and poor academic performance.

So, what can a clinician do? Parents bring their young children to the doctor’s office—a non-stigmatizing and often trusted setting—up to 11 times for well-child visits within the first two years of life. Each of these encounters is an opportunity for pediatric primary care teams to identify unmet social needs among families, link those in need to community resources and coordinate care with community-based social services. Recognizing the importance of this opportunity, the American Academy of Pediatrics (AAP) in 2016 called on its members to begin universally screening for social needs and facilitating connections to community resources as a part of routine care.

The findings in this report provide valuable insights on how to do that work well. Public Agenda has examined parent perspectives that clinicians and other stakeholders should consider when implementing or promoting social needs screening programs. The parents were honest about real-world barriers to screening for social needs in clinical settings. These challenges speak to the need for effective family-centered integration of clinical and community supports for optimum early childhood development. Understanding social needs from parents’ perspective can and should help drive improvement in clinical and community responses.

The UHF Team

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# INTRODUCTION

Health care providers and payers are increasingly taking responsibility for health outcomes and population health through a variety of approaches, including screening for social determinants of health. Just as pediatricians need time and training to integrate these screenings into their practices, parents may not necessarily expect to discuss social needs with pediatricians when they take their children to them for care.

Attempts to integrate social determinants of health screenings into pediatric primary care are more likely to succeed if they are grounded in an understanding of parents' receptivity to discussing social needs and responsive to their concerns about doing so. Yet little research has asked parents, particularly low-income parents, for their perspectives about social determinants of health and how screenings can be implemented successfully. To help fill this gap, Public Agenda, with support from UHF, conducted qualitative research with low-income parents in New York City in an effort to obtain answers to three main questions:

- What are these parents' perspectives on social determinants of health?
- How receptive are they to discussing social needs with pediatricians?
- What are their ideas for making social determinants of health screenings work well?

In eight focus groups, Public Agenda engaged low-income parents in discussion of topics including:

- What do these parents worry about or find challenging when it comes to their children's health and well-being?
- How do their worries and challenges relate to the social determinants of health for which some pediatricians are screening?
- Where can parents go for help in the face of those worries and challenges?
- Do parents view their children's pediatricians as good sources of help with or information about social needs? Why or why not?
- How do parents think pediatricians can successfully integrate screenings for and conversations about social determinants of health into pediatric primary care?

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# METHODOLOGY IN BRIEF

This report summarizes findings from eight focus groups with low-income parents of children ages five years and younger in New York City, conducted in English and Spanish by Public Agenda in July and August 2018.

For four of the focus groups, participants were recruited by a professional market research facility in Manhattan. For the other four, they were recruited by community organizations that are part of UHF's Partnerships for Early Childhood Development (PECD) initiative. All the focus groups lasted two hours, and all participants were compensated for their time and provided with food.

Public Agenda created one moderator guide for use in both sets of focus groups, with flexibility to accommodate differences in emphasis and responses between them. The difference in recruitment ensured that the participants would include parents who were not necessarily clients of community organizations that are part of the PECD initiative. Since analysis of the focus group transcripts indicated that parents' perspectives, experiences and ideas across the two sets of groups were largely similar, data from all eight groups are discussed together in this report. Public Agenda staff moderated all eight focus groups, during which the moderators did not use the terms "social determinants of health" or "social needs." Instead, they used neutral terms like "issues" or "factors."

In the four focus groups Public Agenda conducted at the professional market research facility, all participants were low-income parents who had taken their children to pediatricians during the previous twelve months.<sup>1</sup> In total, 40 parents participated in the groups at the facility. They were recruited to Public Agenda's specifications. All were living in households at or below 250 percent of the federal poverty level. They included residents of all five boroughs of New York City and reflected a diversity of low-income parents in terms of race and ethnicity, age, educational attainment, employment status and frequency with which they had taken their children to pediatricians.

In the four focus groups Public Agenda conducted at community organizations that are part of the PECD initiative—Children's Aid in the Bronx, the Northern Manhattan Perinatal Partnership in Harlem and Public Health Solutions in Queens—all participants were low-income parents of children ages five years and younger, were clients of one or another of those organizations and had taken their children to pediatricians in the previous 12 months. In total, 48 parents participated in these four focus groups. The community organizations recruited the participants, provided space and were compensated by UHF for doing so. Of these four groups, two were conducted at Public Health Solutions in Spanish by Spanish-speaking Public Agenda staff. One group was conducted in English at Children's Aid and one at the Northern Manhattan Perinatal Partnership. Child care for all four groups was available onsite.

For further detail about how Public Agenda conducted this research, please see the methodology section at the end of this report.

<sup>1</sup> Primary care practices serving children comprise a variety of clinical and nonclinical staff, including pediatricians, family physicians, nurses, medical assistants, social workers, community health workers, health coaches and administrative staff. Parents in these focus groups might not have used the same names for professionals' roles that the professionals themselves would use. In this report, the language reflects that used by the parents when referring to their children's physicians—namely, "pediatrician" or "doctor." Parents did not discuss the roles of all professionals in pediatric primary care practices, although they might have interacted with them. Findings 2 and 3 of the report discuss their views about nurses, social workers and administrative staff.

## FINDING 1: WHAT SOCIAL STRESSORS CONCERNED THESE PARENTS?

Parents in the focus groups cited a broad range of social stressors that affected their children's health and well-being, including some that screening tools for social determinants of health may not currently include.

Parents in the focus groups were first asked what they worry about or find most challenging when it comes to their children's health and well-being. The groups began this way to ground the subsequent conversation in the parents' own concerns and to find out how these concerns compared to the social determinants of health for which some pediatricians are screening.

In response, parents in the groups raised many factors they believe affected their children currently and which, they worried, might affect them in the future. Parents seemed acutely aware of the impact of these stressors on their children and often described first-hand experiences with them in their own lives or the lives of friends and family.

*"Mentally, if you're not right, it can really affect your children because it affects the way that you deal with your children."*

Parent from Brooklyn

*"If you're having a lot of legal problems, that affects the kids a lot. If they separate them from you, without [your] knowing where they are, they're just taking them, and it's bad for the children."*

Parent from Queens<sup>2</sup>

*"I have a family member who's going through a domestic violence situation, verbal abuse. It's starting to manifest because my niece is not doing well in school anymore, and she's getting sick and having headaches and migraines."*

Parent from the Bronx

*"Reading to your child is important for children in bilingual households."*

Parent from Manhattan

*"It all affects them. If someone lives under bad conditions, it affects them. It's a chain reaction."*

Parent from Queens<sup>3</sup>

<sup>2</sup> Translated from Spanish.

<sup>3</sup> Translated from Spanish.

**Parents identified many stressors that affect their children:**

- Housing conditions
- Housing affordability
- Parenting strategies for behavioral issues
- Children’s education and day care
- Parents’ mental health
- Parents’ relationships with each other
- Domestic violence
- Single parenthood and shared custody
- Food and nutrition
- Language barriers and learning English
- Bullying and being accepted by other children
- Legal issues, including immigration status
- Reading to a child
- Drug and alcohol use
- Parents’ education
- Neighborhood safety and violence





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After asking focus group participants to generate collaboratively their own lists of worries and challenges related to their children's health and well-being, the moderators shared with them a written list of social stressors.<sup>4</sup> Typically, parents in the groups had already mentioned most of the stressors on the list. The parents agreed all the stressors on the list affect children's health and well-being. Moderators explained to participants that the list comprised issues some parents might find worrisome or challenging but did not indicate it consisted of social needs for which some pediatricians are screening.

**Some stressors parents raised might not typically be included in social needs screening tools, but they nonetheless merit attention.**

- **Single parenthood and shared custody** were challenges some of the parents cited as making it difficult to meet their children's needs. Single parents in the groups talked about the challenges of their relationships with their children's other parent after divorcing or breaking up romantically. They often noted the difficulty of managing busy work and school schedules as single parents, maintaining financial stability on their own and making time to take care of themselves.
- **Neighborhood safety and violence** were worries many parents raised, sometimes in connection with bullying and sometimes in terms of crime, physical fighting and the threat of gun violence in their neighborhoods.
- **Bullying and acceptance by other children** were brought up by a few parents, who framed these as issues their older children faced now and that they anticipated their younger children may face in the future. The parents who raised bullying sometimes expressed concern that it would affect the mental health of their children.
- **Environmental hazards** that a few parents cited included pollution, litter and the possibility of chemicals tainting their children's food.

<sup>4</sup> The list the moderators shared consisted of getting a child into day care; reading to a child; talking to a child; having enough nutritious food in the house; figuring out how to respond when a child misbehaves or has emotional problems; affording rent or dealing with landlords; dealing with housing conditions, like peeling paint, mice or roaches; parents getting an education or learning English; dealing with legal problems; parents getting along and having a good relationship with each other; parents taking care of their own mental health and happiness; someone in the household drinking too much alcohol or using drugs too much.

## FINDING 2. WHAT ROLES DID THESE PARENTS THINK PEDIATRICIANS COULD PLAY IN ADDRESSING SOCIAL NEEDS?

The parents did not immediately identify pediatricians as sources of help with social stressors. Their reactions to the idea of pediatricians discussing these stressors were mixed. They saw some topics, such as nutrition, education and minor behavioral issues, as appropriate to discuss with pediatricians, but others, such as domestic violence, parents' mental health and legal issues, as more sensitive.

To find out whether parents in the focus groups saw pediatricians as potential sources of help with social needs and to gauge how receptive they would be to pediatricians screening for those needs, the moderators asked parents where they would turn for help with the stressors they had raised.

The parents volunteered many potential sources of help and information, giving the impression they believed they knew where to turn when in need. Exploring whether these parents had actually obtained help or information from those sources was outside the scope of this research.

### **Sources parents turn to for help or information with social stressors:**

- Internet searches
- Social media
- Friends and family
- Other parents
- Religious institutions
- Mental health care providers
- Community organizations
- City agencies

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## Parents who had sought help from community organizations and other social service providers valued the support they received.

Some of the parents in the focus groups—including both those in the groups conducted onsite at community organizations and those in the groups conducted at the focus group facility—reported turning to community organizations and other social service providers for help with the issues that worried them or that they found challenging. The parents who had sought such help generally valued it.

*“Where I live, we have a program for the parents. They come in there, like a focus group. And we discuss the problems going on in the neighborhood. We help out each other.”*

————— **Parent from Brooklyn**

*“Whenever I need help, I come here [to Public Health Solutions].”*

————— **Parent from Queens<sup>5</sup>**

*“When I was first pregnant, I had a lot of problems. I went to [a Latina mothers’ group]. They’ve given me a lot of support.”*

————— **Parent from Queens<sup>6</sup>**

*“My family does not support me, okay? And, I’m about to cry now, it’s like I have to trust the people [at the Northern Manhattan Perinatal Partnership]. Thank you for having this for us.”*

————— **Parent from Manhattan**

*“When my wife got pregnant, we had to go to [a Brooklyn-based nonprofit organization], and they would help us with a bunch of things. Once the child was born, they had someone come to the house also, just come and see how everything was going. They taught my wife how to breastfeed.”*

————— **Parent from Brooklyn**



5 Translated from Spanish.

6 Translated from Spanish.

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## Parents generally did not see pediatricians as sources of help with social needs and emphasized the sensitive nature of some needs.

To find out how receptive they were to pediatricians screening for social determinants of health, moderators asked parents whether they thought pediatricians or other clinicians or staff in their offices would be good sources of help or information with the stressors that worried them.

A few parents indicated their children’s pediatricians had discussed social needs with them. While they framed those conversations positively, they emphasized that they had taken place in the context of trusting, long-term relationships with the pediatricians.

*“The difference with my pediatrician, she’s more like a friend to me. I think that the pediatricians need to give their patients more time, and sit and talk to them, and show that they’re really concerned about the person, not trying to get into their business.”*

————— **Parent from Manhattan**

*“When I take my kids to see the pediatrician, she always looks at me and says, ‘How are you feeling? Is everything okay at home? If you need someone to talk to, we have good staff here.’ She’s always tried in case I needed it. They want to make sure that you’re okay.”*

————— **Parent from Brooklyn**

Overall, however, few parents mentioned turning to pediatricians or other health care providers—besides mental health care providers—for help with social needs. This suggests parents who did not mention doing so may not expect to discuss those types of issues with pediatricians, and that the increasingly frequent inclusion of social determinants in health screenings in pediatric care will represent a transition for parents and providers alike.

Parents’ reactions to the idea of discussing social needs with pediatricians were mixed. Most parents in the groups appeared to understand pediatricians would be trying to help by asking about social needs. But many emphasized that pediatricians should approach those discussions carefully and in ways that would allow parents to maintain their dignity.

*“I do like that [social needs] questionnaire. But don’t come right out and go, ‘Do you have mice in your house. Is your kid eating? Is your kid huffing glue?’ No. Ask, ‘Are there any issues at home that you feel could be detrimental to your child’s health? Do you have concerns about your child?’”*

————— **Parent from Brooklyn**

*“We can medicate the child, but I’m still homeless. You don’t have to tell [the pediatrician] exactly what’s been going on if you want to preserve aspects of your personal life. But [you should] still be able to express enough to get the needs of the child met.”*

————— **Parent from the Bronx**

*“All of these are very sensitive topics. I don’t have a problem with them asking the questions, and hopefully they can get me some help. But I also want to know why they’re asking me this.”*

————— **Parent from Manhattan**

*“Sometimes it’s easier when somebody else opens the door than for you to open yourself up—if they ask in a sensitive way.”*

————— **Parent from the Bronx**

Parents in the groups drew distinctions among different types of social stressors; see table below. Many agreed they would be fairly comfortable discussing some topics with pediatricians. For other topics, participants were divided on or unsure whether their children's pediatricians could help. Therefore, they questioned whether it was worth the effort to discuss those topics with them. Finally, there was a set of topics that most parents viewed as particularly sensitive. These were very salient for the parents and occupied much of their attention in the focus group conversations. Many said discussing these topics could make them feel uncomfortable or ashamed, and that doing so could have negative consequences for their families—a concern discussed in Finding 3.

*"Some things, if my pediatrician was to ask me, I'd be like, it's none of your business. It's nobody's business to ask me that."*

Parent from Brooklyn

*"I think it depends. There's people who don't want to talk about their private life."*

Parent from Queens<sup>7</sup>

*"You might have the best intention with your question, but that person may not see it that way."*

Parent from Brooklyn

Parents felt some social needs were more sensitive than others.

**Comfortable Discussing with Pediatricians**

**Particularly Sensitive**

**Not Sure Pediatricians Could Help**



7 Translated from Spanish.

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## Parents said they would prefer discussing social needs with pediatricians rather than with other professionals in clinical settings.

The moderators tried to gauge parents' receptivity to discussing social needs with various members of the primary care team. When asked specifically how they would feel about discussing social needs with nurses, most indicated a preference for discussing them with pediatricians.

*"That's for the doctor to know."*

————— **Parent from the Bronx**

Separately, the moderators asked parents in the groups how they would feel about discussing social needs with administrative staff in pediatric offices. The parents were very clear that they did not want administrative staff to know sensitive information about them or their social needs. They often described administrative staff as judgmental of people enrolled in Medicaid or prejudiced against the parents on the basis of race or ethnicity.

*"The staff are the ones who just don't behave well with us because we're Latinos."*

————— **Parent from Queens<sup>8</sup>**

*"Some people seem like they don't want to be there, and they have an attitude and make you feel that they would look down on you if you asked for some of these services."*

————— **Parent from Manhattan**

*"A receptionist, the nurse, they're often on a time crunch. So they may not be very sensitive to getting the right questions. But if the doctor was to ask me some of these things, I know that they're asking me toward the betterment of my child. So, that fosters our relationship, as opposed to the receptionist."*

————— **Parent from Manhattan**

8 Translated from Spanish.

## FINDING 3. WHY DID PARENTS THINK DISCUSSING THE MORE SENSITIVE SOCIAL NEEDS WITH PEDIATRICIANS WOULD BE DIFFICULT?

Parents' concerns about discussing sensitive social needs with pediatricians included worries about being judged and discriminated against, fear of intervention by a child welfare agency, lack of time during appointments and frustration at the prospect of disclosing sensitive information without getting help.

For most parents in these groups, the idea of discussing social stressors with pediatricians was unfamiliar. They generally understood why pediatricians would be asking about these stressors, but many emphasized the need for them to approach the topics with sensitivity. Furthermore, the prospect of discussing some social stressors provoked wariness among most parents.

The focus group moderators sought to understand parents' concerns so pediatricians could understand and address them. The final section of this report details parents' ideas for how pediatricians can approach these discussions in ways that are productive and welcoming for parents and families.

### Parents' concerns about discussing sensitive social needs:

- Parents worried about being judged and discriminated against.
- Parents feared that sharing information could trigger intervention by a child welfare agency.
- Short appointments and long waits could make it difficult for parents to discuss complex problems.
- A double loss: Disclosing sensitive information without getting help might frustrate parents.

### Parents worried about being judged and discriminated against.

Many parents in the focus groups described past experiences in which they felt judged and discriminated against by health care providers, including but not limited to their children's pediatricians and nurses and administrative staff in pediatricians' offices. The parents often indicated that those previous negative experiences put them on guard with all health care providers, including pediatricians, and could make them wary of opening up about sensitive topics. Beyond health care, several parents described feeling discriminated against and, hence, mistrustful of legal, educational and social service institutions as well.



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Parents mentioned a range of reasons they have felt judged or discriminated against by health care and other institutions, including being enrolled in Medicaid, being low-income or being African American or Spanish-speaking. A few parents mentioned being aware of the income difference between them and their children's pediatricians.

*"There is a lot of insensitivity among doctors, which makes it hard to ask questions like this. There is an issue of arrogance. So it's hard to get comfortable enough with a doctor to answer some of these questions."*

————— **Parent from Queens**

*"Someone might come in, maybe they didn't speak really good English, and the assumption might be there that they're getting housing assistance, or they receive food stamps or they're failing at parenting, which is totally not true. There are good and bad parents everywhere, but there might be an assumption based on Medicaid or lack of certain clothing brand names."*

————— **Parent from Brooklyn**

These parents were highly attuned to verbal and nonverbal cues they felt subtly signaled disrespect from pediatricians, nurses or administrative staff. In the focus groups, they often dramatized the eye rolls, tones of voice and comments under the breath that they felt were directed at them in pediatricians' offices.

*"Oh, you have Medicaid?"*

————— **Parent from Brooklyn**

*"Are you all living in a safe environment? Is anybody going through domestic violence? You're asking me these questions? No. You're being judgmental."*

————— **Parent from Manhattan**

*"Oh, your child is not rolling over yet? He should be rolling over."*

————— **Parent from the Bronx**

When the moderators explained at the end of the groups that some pediatricians are beginning to screen for social determinants of health and asked parents for their advice to them about how to do so, they overwhelmingly focused on trust, empathy, compassion and listening, as discussed in further detail in Finding 4.

*"First, more than anything else, the pediatrician should earn your trust."*

————— **Parent from Queens<sup>9</sup>**

*"You can have an education, but you also have to be a people person."*

————— **Parent from Queens**

*"We need more genuine doctors who really care. If we don't feel like you care, I'm not going to give you my information."*

————— **Parent from the Bronx**

9 Translated from Spanish.



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## Parents feared that sharing information could trigger intervention by a child welfare agency.

While parents in these focus groups expressed mistrust of many institutions, the local child welfare agency unfortunately loomed large for them as a threat to their families. Many told us they would be afraid to share information with pediatricians about more sensitive stressors—particularly, but not exclusively, legal issues and domestic violence—because they were afraid of being investigated by the child welfare agency and losing custody of their children.

*“I would like to talk to the doctor and maybe to have advice, but I don’t know. It scares me. Because there can be so many degrees of flack. You don’t know what is going to be perceived as wrong.”*

————— **Parent from Manhattan**

*“We are all as parents afraid of this. If I went to the doctor and they were like, ‘Oh, we’re going to follow this up with a social work visit,’ then I’m out the door. It’s like when you hear ‘fire,’ you think, run.”*

————— **Parent from the Bronx**

*“You have to be careful what you tell the doctor. It may be used against you.”*

————— **Parent from Brooklyn**

*“You might be opening up a whole, brand-new can of worms for yourself. If something gets misperceived, now you’ve got yourself a whole bunch of problems, and you haven’t done anything wrong.”*

————— **Parent from Queens**

Several parents in the groups talked about friends, family members and neighbors who had been investigated by the child welfare agency, and a few said they had been investigated themselves. Redirecting conversations and withholding information were among the ways participants said they would try to protect their families from what they saw as risks that pediatricians might report them to child welfare.

*“I’m afraid of honestly speaking. I’m afraid that they’re going to try to take my child away. I have to be careful how I answer those questions.”*

————— **Parent from Manhattan**

*“I don’t say nothing. You don’t say nothing because you’ve got to avoid consequences. There’s certain things you can’t tell them.”*

————— **Parent from the Bronx**

*“In these times [all] it takes [is for] a wrong sentence to be misconstrued.”*

————— **Parent from the Bronx**

Although social workers are trained to provide help with exactly the challenges low-income parents may face, parents in these groups often associated social workers with the local child welfare agency and, hence, with the risk of losing their children. They did not want social workers present in exam rooms and expressed fear of being referred to them. Pediatricians and social workers should be aware that social work can connote risk to some parents. As discussed in Finding 2, however, those who had sought help from community organizations and social service providers valued the support they had received. This suggests that creating opportunities for parents to build trusting relationships with social workers is possible and can benefit the parents.

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## Short appointments and long waits could make it difficult for parents to discuss complex problems.

Many parents noted that pediatric care appointments are short. Given the limited time, parents often said it was important to let doctors focus on the medical aspects of the visit rather than, as one participant put it, “dumping all their problems on the doctor.”

*“A doctor sees so many patients in a single day. They don’t have time. They can easily confuse one patient for the next.”*

————— **Parent from Queens.**

Parents explained they spent considerable amounts of time getting to appointments and waiting for them to start, with children who might be sick and sometimes with siblings in tow as well. They said they would not hesitate to redirect conversations away from social needs to what they felt were their main medical concerns.

*“I’m never at the doctor without more than one child. We don’t have time to get personal. We’ve got to check up this child, check up that child, run over to get prescriptions. We don’t have time to get into personal business.”*

————— **Parent from Brooklyn**

*“We spend four hours there. I can’t keep three children under four [years old] in a clinic, in a place for four hours like that.”*

————— **Parent from the Bronx**

*“If you waited a long time to see [the doctor], once you get called, you want to be able to do what you need to.”*

————— **Parent from the Bronx**



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## A double loss: Disclosing sensitive information without getting help may frustrate parents.

The term “double loss” describes the frustration many parents in these groups expressed about the prospect of disclosing sensitive information without getting help in return. They framed the disclosure itself as one loss and not getting help as a second loss. Parents in the groups often said that if doctors are going to ask about social determinants of health, they should be able to offer help. They generally did not want to just “talk it out.”

*“If you’re going to ask these questions, at least have some solutions. Don’t just ask, or I’ll think I shouldn’t say any more.”*

————— **Parent from Brooklyn**

*“Why ask if there’s not help at the end?”*

————— **Parent from Manhattan**

*“Not to say that [pediatricians] shouldn’t be concerned about some of these things, because a lot of these things are very detrimental to a child’s health and mental stability. It’s just that if there is no assistance coming after the question, I really don’t think that should be your objective with this visit that I scheduled about my child.”*

————— **Parent from Queens**

*“If they can help you, then I think more people would feel more comfortable sharing.”*

————— **Parent from Queens**

When it came to housing affordability and legal issues in particular, parents did not see how a pediatrician could possibly help them, making them particularly unwilling to go through the effort of discussing those topics.

*“How could they help you afford your rent or deal with a landlord?”*

————— **Parent from the Bronx**

*“Realistically speaking, the doctor can’t help me with rent issues or legal issues. I know where I can go to get that stuff.”*

————— **Parent from Queens**

*“If you have these types of problems, you’ll not really go to the doctor. I don’t think the doctor is really going to help me with my rent and my legal problems.”*

————— **Parent from Queens**



## FINDING 4. HOW DID THESE PARENTS THINK PEDIATRICIANS SHOULD DISCUSS SOCIAL DETERMINANTS OF HEALTH WITH THEM?

Parents' recommendations for pediatricians about discussing social determinants of health included building trust, choosing the right moment and making clear that screening is standard protocol.

Despite the concerns they cited about discussing social needs with pediatricians, particularly their more sensitive needs, most parents in these groups responded enthusiastically when the moderators asked for their ideas about how pediatricians should approach discussing social determinants of health.

### Parents' recommendations for pediatricians:

- Build trust.
- Choose the right moment for parents.
- Not in front of the children.
- Let parents choose to learn about helpful resources at their own initiation.
- Signal confidentiality and be transparent about what triggers reporting to child welfare.
- Do not ask just for the sake of asking.
- Make clear that screening is standard protocol.
- Consider "letters of support" and other ways to be parents' allies.

### Build trust.

Parents in the groups emphasized that talking openly about social determinants of health with pediatricians is a matter of building trusting relationships. While some parents said they would prefer discussing social determinants of health with pediatricians face to face and others said they would prefer a questionnaire, their overriding message was that they could only share information about sensitive topics in the context of a trusting relationship with their children's pediatricians. A few parents in the groups mentioned that seeing photos of their pediatricians' own children displayed on office walls or desks could help build trust because it signaled that those pediatricians knew how hard parenting is.

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### **Choose the right moment for parents.**

With long waits for short appointments, parents felt pediatricians should choose the right moment to start conversations about social needs. They emphasized that if they come to an office visit with a child who has a cold or other immediate concern, the pediatrician should address that concern and wait for another visit, when they might have the time and energy for the conversation, to bring up more sensitive, complex topics.

### **Not in front of the children.**

Parents said that if they were to discuss social determinants of health with their children's pediatricians, they would prefer to do so in private, not in front of their children. As one parent said, "Problems between adults should always be discussed with adults." They emphasized that privacy is especially important when conversations concern whether parents are getting along with each other or parents' mental health. They said pediatric offices should create dedicated spaces where children can play, giving adults time and space to discuss sensitive, complex topics, as well as easing the burden of long waits for appointments with sick children or siblings. Parents also wanted offices to have bright décor, helpful signage and welcoming clinicians and other staff.

### **Let parents choose to learn about helpful resources at their own initiation.**

Parents often said they wanted posters on waiting room or exam room walls and pamphlets they could take themselves. They said posters and pamphlets would let them choose to learn about social needs—particularly more sensitive ones—and about helpful resources on their own time, discreetly and at their initiation.

### **Signal confidentiality and be transparent about what triggers reporting to child welfare.**

Parents in these groups understood that when a child is truly in danger, a pediatrician must share that information with the appropriate authorities. But they also wanted pediatricians to be transparent about what triggers reporting and what does not, so they would know which issues they could talk about openly. They also felt strongly that when they share sensitive information, it must be kept confidential. Signage directing staff to respect patients' privacy could not only help remind staff about confidentiality but could also signal to parents that pediatricians take confidentiality seriously—another way to build trust.

### **Do not ask just for the sake of asking.**

Parents were very firm in their conviction that if pediatricians ask about sensitive issues, they should be willing and able to provide or suggest helpful resources. Parents wanted to avoid the double loss of disclosing sensitive information without receiving help. They did not want to just be handed a phone number. They said referrals to other organizations should come with an offer of guidance and a warm handoff.

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### **Make clear that screening is standard protocol.**

It was very important to parents in these groups to be assured that everyone gets screened—whether face to face or with questionnaires—not just those who appear to be struggling, are enrolled in Medicaid or are low-income. Otherwise, parents said, they would feel judged or profiled.

### **Consider “letters of support” and other ways to be parents’ allies.**

Despite their worries about discussing social determinants of health with pediatricians, parents in these groups indicated that the doctors nonetheless have a unique authority and can be their allies in difficult situations. Parents specifically said it could be helpful for pediatricians to provide what they called “letters of support”—for instance, when they face problems with the public housing authority or private landlords regarding peeling paint, pests or other environmental hazards—attesting to how these risks affect their children. Some parents said pediatricians could vouch for them when they face legal difficulties or child welfare investigations, attesting that they are good parents who are trying their best and should not lose custody. Focus group moderators hypothesized that writing these letters could build trust between pediatricians and parents by showing parents that their children’s doctors are on their side, and it could even restore some trust in health care institutions that parents might otherwise regard suspiciously.



## CONCLUSION

Pediatricians, along with other health care providers, are increasingly being asked to identify and help address social determinants of health. These efforts represent a transition for both the pediatricians and for parents. It is crucial for pediatricians to understand parents' needs, concerns and goals as both parties adjust to this expanded vision of pediatric care. Pediatricians and their staffs must work with parents to build their comfort with disclosing information about social stressors, particularly those that are most sensitive.

The low-income parents in our focus groups understood their children were affected by the social determinants of health for which some pediatricians are screening. But they did not immediately identify pediatricians as sources of help with social needs—perhaps because few of them indicated having experienced pediatric care that attempted to address those needs. Parents' frustration at the prospect of disclosing sensitive information without getting help may stem in part from their not expecting pediatricians to be able to help with those issues.

Many of these parents' ideas for pediatricians about how to discuss social needs would likely strengthen the quality of pediatric primary care more generally—in particular, building long-term trusting relationships between parents and pediatricians. Addressing short appointments and long waits could also promote higher quality care if doing so created more time to discuss social needs and freed parents to take care of priorities like work or school rather than waiting for appointments to start.

Parents' fear of child welfare agencies may be a particularly difficult challenge for pediatricians who want to screen for social determinants of health, given the high stakes involved. Parents in these groups worried about losing custody of their children if they disclosed information about some of the very social needs that can be most important for health and well-being. Parents' suggestion that pediatricians should be transparent about what does and does not trigger reporting, however, could help allay at least some of their fears and could help build trust between them and pediatricians. Making clear that screening is standard protocol might begin to address low-income parents' feelings of being discriminated against and judged. Lastly, attempts to screen for social determinants of health may be more successful if pediatricians develop partnerships with the community organizations and other social service providers that low-income families already trust and turn to for information and help.

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This qualitative research provides rich insight into low-income parents' views on social needs and screenings. These findings should inform future research and interventions focused on making sure screenings for social determinants of health meet the needs of parents and children. As a follow-up, a survey of low-income parents could explore how they rate the relative importance of various stressors and how widespread the fear of child welfare agencies is. A survey could also explore whether low-income parents' views vary by factors such as race and ethnicity, the quality of their relationships with their children's pediatricians, parents' and children's health status, and parents' previous experiences with health care and social service systems.

As social determinants of health screenings become more common in pediatric primary care, qualitative and quantitative research can help us understand parents' experiences of those screenings and can continue to engage parents in conversations about how to promote their children's health and well-being by addressing social needs.



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# METHODOLOGY

This report summarizes findings from eight focus groups with low-income parents of children ages five years and younger in New York City, conducted in English and Spanish by Public Agenda in July and August 2018.

**Background Research:** Before designing the focus group moderator guide, Public Agenda staff reviewed previous research about social determinants of health in pediatric care, conducted eight interviews with pediatric primary care practitioners, and consulted staff at the community organizations where four of the focus groups were conducted.

To refine the research goals, Public Agenda staff held meetings with UHF staff, who then reviewed drafts of the focus group moderator guide. Public Agenda staff also held meetings with staff of the community organizations at which we planned to conduct the focus groups, to improve our understanding of the populations they served. Public Agenda staff created one moderator guide for use in both sets of focus groups, with flexibility to accommodate differences in emphasis and responses between them. The moderator guide was shared with the community organizations' staffs if they requested it. During the focus groups, the moderators did not use the terms "social determinants of health" or "social needs." Instead, they used neutral terms like "issues" or "factors."

**Focus Groups:** For four of the focus groups, participants were recruited by a professional market research facility. Public Agenda staff moderated the groups at that facility. For the other four, participants were recruited by community organizations that are part of UHF's Partnerships for Early Childhood Development (PECD) initiative. Public Agenda staff moderated the groups onsite at those organizations. The difference in recruitment ensured the participants would include parents who were not necessarily clients of community organizations connected with the PECD initiative. Public Agenda's research team collaboratively developed a coding scheme and coded the focus group transcripts using Dedoose qualitative analysis software. Since analysis of the transcripts indicated that parents' perspectives, experiences and ideas across the two sets of focus groups were largely similar, data from all eight groups are discussed together in this report.

**Focus Groups at the Market Research Facility:** In total, 40 parents participated in the focus groups at the market research facility, which was in Manhattan. All participants were low-income parents of children ages five years and younger who had experience taking their children to pediatricians.<sup>10</sup> Participants were recruited to Public Agenda's specifications so that all were living in households at or below 250 percent of the federal poverty level. They included residents of all five boroughs of New York City and reflected a diversity of low-income parents in terms of race and ethnicity, age, educational attainment, employment status and frequency with which they took their children to pediatricians. Four of the participants across these groups were fathers, and the rest were mothers. Grandparents were not included.

<sup>10</sup> Primary care practices serving children comprise a variety of clinical and nonclinical staff, including pediatricians, family physicians, nurses, medical assistants, social workers, community health workers, health coaches and administrative staff. Parents in these focus groups might not have used the same names for professionals' roles that the professionals themselves would use. In this report, the language reflects that used by the parents when referring to their children's physicians—namely, "pediatrician" or "doctor." Parents did not discuss the roles of all professionals in pediatric primary care practices, although they might have interacted with them. Findings 2 and 3 of the report discuss their views about nurses, social workers and administrative staff.

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Potential participants were excluded if they worked in health care, health insurance, the pharmaceutical industry or health advocacy or if they had participated in a focus group within the previous six months.

The focus groups at the market research facility were conducted in English and lasted two hours. All participants were compensated for their time and provided with food. These focus groups were video recorded and professionally transcribed.

**Focus Groups at Community Organizations:** Public Agenda staff conducted four focus groups onsite at Children’s Aid in the Bronx, the Northern Manhattan Perinatal Partnership in Harlem, and Public Health Solutions in Queens, to which Public Agenda was connected by UHF. The community organizations recruited the participants, provided space and were compensated directly by UHF for doing so.

In total, 48 parents participated in the focus groups at the community organizations. All participants in these groups were parents of children ages five years and younger and clients of one or another of the community organizations and had experience taking their children to pediatricians. Three of the participants across the groups were fathers, and the rest were mothers. Grandparents were not included.

The focus groups lasted two hours. The participants were compensated for their time. Food and child care were provided, and some parents kept their children with them during the groups. The focus groups were audio recorded and professionally transcribed.

Of the four groups conducted at community organizations, two were conducted at Public Health Solutions in Spanish by Spanish-speaking Public Agenda staff. One was conducted in English at Children’s Aid and one at the Northern Manhattan Perinatal Partnership. Transcripts of the groups in Spanish were professionally translated into English.

More information about this study can be obtained at [www.publicagenda.org/pages/its-about-trust-low-income-parents-perspectives-on-how-pediatricians-can-screen-for-social-determinants-of-health](http://www.publicagenda.org/pages/its-about-trust-low-income-parents-perspectives-on-how-pediatricians-can-screen-for-social-determinants-of-health) or by emailing [research@publicagenda.org](mailto:research@publicagenda.org).

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# ACKNOWLEDGMENTS

The authors of “It’s About Trust” would like to thank the following individuals and organizations for their support and contributions to this research:

The focus group participants who took the time to share their views and experiences with us;

Children’s Aid, the Northern Manhattan Perinatal Partnership and Public Health Solutions, who helped to organize four of these focus groups and who shared their space, time and expertise with us, especially Adriana Alba, Lucie Kadage and Rachel Schwartz;

The United Hospital Fund, which supported this research, especially Suzanne Brundage, Lee Partridge, Matlin Gilman, Deborah Halper and Chad Shearer;

The pediatric care providers and community organizations who are members of UHF’s PECD initiative for their helpful feedback when Public Agenda staff presented these findings to them in February 2019.

Nicole Cabral and Jennifer Orellana, from Public Agenda’s public engagement team, who helped to organize and facilitate the focus groups at Children’s Aid, the Northern Manhattan Perinatal Partnership and Public Health Solutions;

Vania Andre, Brian Scios and Cynthia Spence for bringing these findings to the attention of a broad audience;

Rebecca Silliman from Public Agenda’s research team;

and Will Friedman, president of Public Agenda, for his vision, insight and guidance throughout this project.



#### **About Public Agenda**

Public Agenda helps build a democracy that works for everyone. By elevating a diversity of voices, forging common ground and improving dialogue and collaboration among leaders and communities, Public Agenda fuels progress on critical issues, including education, health care and community engagement. Founded in 1975, Public Agenda is a nonpartisan, nonprofit organization based in New York City.

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