Putting The T In Mlp: The Role Of Trust In Medical Legal Partnerships

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Putting the T in MLP: The Role of Trust in Medical Legal Partnerships

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A thesis submitted in partial fulfillment of the requirements for a Master of Public Health

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Abstract

The United States spends more on healthcare than any other country, while health outcomes lag behind many nations. This is often attributed to the disproportionately low spending on social services, and social determinants of health (SDOH) need to be addressed in order to improve the nation’s health. SDOH are increasingly understood to be key factors in predicting health outcomes. Medical legal partnerships (MLPs) are one intervention that seek to address SDOH. The MLP model comprises three core components: providing legal care for patients, improving systems of healthcare, and creating policy change outside the healthcare system. In this qualitative study, we interviewed caregivers of children who have received legal care through the MLP at the Yale Pediatric Primary Care Center. After coding and analyzing these interviews, we came to several important conclusions. Assessing the relationship between patient and provider, we found that a lack of trust in this relationship led to decreased disclosure of health-harming legal needs. We also found that once participants did disclose their needs and connect to legal care, they gained agency and empowerment with the healthcare, legal, and educational institutions. Lastly, participants expressed that after receiving legal help, they then disseminated information into their communities. These findings suggest that improved methods to promote trust are needed when developing MLPs and performing screeners to assess SDOH.
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Background

The United States spends more on healthcare than any other country. Yet, health outcomes lag behind many developed, and in some cases, underdeveloped nations. This paradox is often attributed to the disproportionately low spending on social services (Heiman & Artiga, 2015; Bradley & Taylor, 2015). While healthcare spending is a determinant of health outcomes, social determinants of health (SDOH) need to be addressed in order to improve the nation’s health. SDOH refer to the conditions in which “people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels” (Social Determinants, 2017). SDOH are increasingly understood to be key factors in predicting health outcomes. SDOH, including poverty, education, segregation, and social support, account for greater than 33% of the deaths in the United States in one year (Heiman & Artiga, 2015).

Medical legal partnerships (MLPs) are one intervention that seek to address SDOH. MLPs represent an innovative model of care that originated in 2003 at the Boston Medical Center, where healthcare and legal providers began offering legal services to pediatric patients and their families to address health-harming legal needs (Sandel et al., 2010). MLPs integrate legal care into the healthcare system and promote collaboration between healthcare and legal providers (Lawton & Sandel, 2014). The MLP model comprises three core components: providing legal care for patients, improving systems of healthcare, and creating policy change outside the healthcare system (Sandel, et al., 2010). MLPs are most often multidisciplinary, and may include a variety of providers, including paralegals, social workers, case managers, nurses, mental healthcare providers, lawyers, law students, residents, primary care providers, and administrators, among others (McCabe & Kinney, 2010). This model varies: some MLPs serve a
specific population (children, veterans, undocumented immigrants), others focus on a specific legal area, such as housing or immigration, or a specific health condition, such as asthma, HIV, or sickle cell disease (Benfer, Gluck, & Kraschel, 2018). The legal team may work onsite at the health facility fulltime or once a week. Referrals most often originate from the healthcare side, as medical providers identify a patient or family with a particular concern, but occasionally they may initiate from the legal side.

MLPs often serve populations with high levels of need for legal care. An estimated 50-85% of patients at community health centers have some kind of health-related legal need (Shin, Byrne, Jones, Teitelbaum, & Repasch, 2010). The most common needs concern family law, housing, and health insurance eligibility, and those most likely to require this assistance are those patients who are uninsured, on public insurance, and those who are disabled or have chronic health conditions (Shin et al., 2010). One-quarter of those Americans who live on 125% or less of the federal poverty line reported having six or more legal concerns in 2017 (Legal Services Corporation, 2017). Furthermore, of the civil legal issues reported in 2017 by Americans living on 125% or less of the federal poverty line, 86% did not receive any or adequate legal assistance (Legal Services Corporation, 2017).

MLPs have well-documented positive outcomes on people’s health-harming legal needs and other SDOH. Some examples of MLP effectiveness include improved housing conditions for children living in substandard housing, potentially reducing triggers of chronic disease (Beck et al., 2012), access to benefits for families of children with sickle cell disease (Pettignano, Caley, & Bliss, 2011), and improved access to preventative healthcare care and concrete supports, including food stamps, housing vouchers, and utilities assistance, for low-income families with infants (Sege et al., 2015).
Research also finds that MLPs may reduce stress levels among their clients. For example, one study evaluated participants’ stress levels who received care from an MLP in a primary care setting, in which the researchers used a validated quantitative screener, the Perceived Stress Scale (PSS-10), and found that people’s reported stress was reduced after having received legal services through an MLP (Ryan, Kutob, Suther, Hansen, & Sandel, 2012). Another study of an MLP providing care for patients with cancer reported that 75% of the participants had reduced stress levels, and half of the participants who responded said that the legal services had a “positive effect” on their families and loved ones (Fleishman, Retkin, Brandfield, & Braun, 2005). In another study, participants who had received legal care through an MLP completed the PSS-10, as well as “Sources of Stress” questionnaire that the authors created in order to see the changes in people’s stress sources. The authors found a reduction in feelings and sources of stress after receiving legal care (Rosen Valverde, Backstrand, Hills, & Tanuos, 2018). These studies, while addressing MLPs’ effects on stress levels of the participants, do not however delve deeply into how MLPs lead to intangible benefits for participants.

This growing literature suggests that MLPs may have significant and positive impacts on population health. However, this mostly quantitative literature focusing on particular health and legal outcomes likely does not capture the wider impact that MLPs have on the lives and well-being of patients. In particular, missing is in-depth research on how MLPs affect the relationships between patients and their providers, and the impact of these relationships on health outcomes. Studying this aspect of the MLP model is essential so that the facilitators and barriers to these relationships can be elucidated in order to promote more efficacious and trusting relationships to improve SDOH. Furthermore, it is important to know specifically what
facilitators and barriers may exist to a provider’s determination of a patient’s needs. These details can better enable providers to identify the most appropriate referrals and services.

MLPs involve various actors, relationships, and institutions, and involve complex interactions in order to achieve success. Those who receive MLP services have multifaceted relationships with their providers, whether legal or healthcare, and often have historically difficult relationships with institutions due to their social or economic background, which may inhibit their disclosure of SDOH. The first step to identify needs within an MLP is to effectively screen for SDOH. In this paper, we draw on qualitative interviews with caregivers of children who have received care through an MLP to understand how their relationship with an MLP shapes relationships with institutions, and what barriers exist to establishing that relationship. This research will also interrogate how relationships with institutions can be fostered in order to effectively implement an MLP. Finally, this paper will explore the downstream effects of receiving care through an MLP on individuals and communities.

Methods

This study takes place in New Haven, Connecticut with caregivers of pediatric patients who have received services through the Medical-Legal Partnership at Yale New Haven Hospital’s Pediatric Primary Care Center (PCC). In this model, an attorney, Alice Rosenthal, works at the PCC and receives referrals from pediatric providers for patients who are experiencing one or more health-harming legal needs. Before initiating recruitment to the study, an interview guide was developed by the researchers in collaboration with the MLP attorney and a pediatric medical provider from the PCC. In order to recruit participants for qualitative interviews, several methods were used: first, the MLP attorney created lists of families to whom she had provided legal services. Using these lists, the researchers contacted families by letter to
see if they were interested in participating in the study. Additionally, the MLP lawyer referred caregivers directly to the researchers. Lastly, some participants were recruited through snowball sampling.

We conducted seventeen semi-structured interviews between July 2018 and March 2019, in New Haven, East Haven, Hamden, and New Britain, CT. We conducted the majority of the interviews in English, with a few in Spanish. We asked participants about their experience working with the MLP specifically, as well as about their overall experiences with their children’s healthcare. We also asked other questions about their relationships to institutions – educational, justice, and healthcare. We compensated participants $50.00 for their time. Women of color comprised all of the interviews, and they were either mothers or grandmothers of PCC patients. An external company then transcribed the interviews. We used group discussion between the author and researchers to develop general themes. The author then created a codebook, using Dedoose, and applied the codes to the transcripts. Following this, the author used these codes to develop the results section of this paper.

**Findings**

The interviews conducted demonstrate both the barriers and facilitators to building trust between participants and providers. They demonstrate that through the process of accessing legal services at a pediatric clinic, participants established strong, trusting relationships with their children’s medical providers, in whom they confided and discussed their obstacles. These improved and profound relationships with their medical and legal providers at times led to changes in relationships with other institutions: participants had increased confidence in institutions and were better able to navigate institutions through increased knowledge, self-
advocacy, and empowerment. Participants also used this knowledge and increased agency and empowerment to spread information and become organizers within their communities.

**Relationships**

**Barriers to Trust**

The relationship between patients and medical and legal providers within an MLP is pivotal. Without trust, respondents were less willing to discuss the SDOH that lead to health-harming legal needs, precluding the identification and treatment of these needs. Many respondents discussed their lack of trust in their children’s healthcare providers, and they often initiated relationships with their providers with a sense of protectiveness and guardedness. Due to fraught relationships with the Department of Children and Families (DCF), the police, school systems, and other institutions, some respondents feared sharing their concerns about their children with their healthcare providers. For example, when asked if she discussed her experiences and challenges with her provider, Kylie said that she did not because “I don't like telling people my business, 'cause some people use it against you, and I don't have time for that.” As this quote illustrates, healthcare institutions do not represent health and safety to everyone, but rather authority, regulations, and potential discipline. Kylie said, “I don't deal with a lot of people, because I feel like you're gonna call DCF on me, so I don't – I won't deal with you. Like, I'm real skeptical.” Sara also mentioned that she “was really worried that the doctors might call DCF.” Even when Nia was in the dire situation of facing an eviction, she was reluctant to talk to her provider: “I didn’t feel comfortable bringing it up, you know? I just kinda like had a I’ll-do-it-myself mentality, you know? It wasn’t … I didn’t feel like … I didn’t feel comfortable with letting anybody in on what I was dealing with.” Nia said, “I didn’t wanna speak to anybody because it’s the circumstance is kinda personal… I was very much concerned that I would be
looked at or viewed differently” once she divulged her eviction notice to her child’s healthcare provider.

Participants also described fearful and adversarial relationships with legal institutions including family court and DCF. For example, when Sequoia discussed her conversations with her lawyer, she said, “sometimes, I would be afraid that it would backfire on me.” Sequoia described her hesitation in telling her lawyer that her son, who has learning delays, was abused by a teacher at school. She was concerned that involving the legal system could impugn her reputation: “I didn't want it to affect my profile as a parent, her, possibly the news getting involved with this.” Even though her son was hit at school, the potential of damage to her as a parent was a powerful deterrent to divulging this information. Participants also reported negative perceptions of legal help that inhibited their disclosure of personal details. Nia said, referring to legal help, that “I thought they would be kinda you know uptight and not only uptight but just like I didn’t know too much about it.” Nia’s lack of familiarity with legal counsel is a reflection of the fact that disenfranchised people often do not have easy access to the legal system.

Some of the patients’ lack of trust in providers is related to the type of healthcare setting in which they receive care. The experience of receiving healthcare at Yale New Haven Hospital, an academic teaching institution with a focus on research, led to participants feeling like experiments and exploited. In discussing her experience with providers, Amy said, “I'm not going to lie, at first I was very skeptical because there's at Yale there's a lot of people come in that they do studies.” As some participants have encountered so many providers and students verbally or physically prodding them to serve research purposes, they are set up to be defensive, especially concerning their children. Participants have tired being asked to be part of studies. Kylie said that her willingness to share information with medical providers “depends on the
questions and it depends on if I’m not gonna get offensive by the questions.” Respondents may perceive questions about their children’s health and wellbeing as overly invasive or not germane to their children’s care. Furthermore, may encounter a new provider at every visit, promoting a feeling of lack of continuity of care. Marlena said that “you get a different personality every resident. So, you know 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. They're all different.”

An open relationship can be a determinant of good care, and can affect whether legal needs are identified and appropriate referrals made.

Another reason that participants may distrust their providers are the questions they ask. Some of these are the (seemingly) benign questions that are built into the healthcare system. Some legal and medical questions can be perceived as overly invasive and lead to question fatigue. An essential aspect of an effective MLP is information gathering and issue identification. Questions are asked in order to collect information about SDOH and to identify potential needs and health harming legal issues. Though providers are trained to ask probing and intimate questions about safety, households, and relationships, this can be inferred as a lack of trust in parents. When Amy met her pediatrician, she noted, “I didn't like the questions. And I don't like how Yale does that.” Even when the participants understood that the provider must ask the question, Amy remarked, “it makes someone feel that they're looking at – they're judging them and looking at someone as – you know what I mean? When somebody asks me, ‘Are you safe at home?’ in my mind the first thing that I think of is ‘What are you seeing that I'm not seeing? Do I look like an abused person? Do I look sad or depressed?’ And maybe I did look sad or depressed but it was mainly because of my daughter's health.” These questions made respondents feel judged and stigmatized, even while they are asked with the intention of identifying areas of
need. Amy said that she “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?’” Amy was overwhelmed with the quantity and type of questions asked. While knowing information is intrinsic to providing care, the repetition and types of questions may be a source of stress itself.

Several of the respondents described negative interactions when they felt that their providers did not relate to them. These negative interactions resulted from the patient’s perception of a provider’s lack of understanding the social needs of their patients. In each case, the result was a break in trust in the patient-provider relationship. Tiana was living in housing with harmful mold, which caused her daughter to become very sick. When she first tried to address this with her child’s healthcare providers, she described the situation and said that “I was trying to explain it to the doctors, but they couldn't really understand it.” When Jasmine disclosed her concerns to her child’s healthcare provider, she was told: “‘We can't help. Try 2-1-1, 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.” This answer frustrated Jasmine and left her feeling resourceless. Kylie said that “I always feel my guard's up, because I feel like somebody gonna come at me or talk to me crazy, I'm – I'm not dealing with it.” These quotations demonstrate a lack of trust in and openness with medical providers, leading to less identification of needs, and thus fewer connections and referrals to needed services. This must be addressed when considering an intervention to connect people to legal services.

**Earning Trust, Assuring Confidentiality**

Some participants who utilized the MLP eventually revealed their predicaments to their providers in order to obtain legal help. The interviews demonstrated how healthcare and legal
providers eventually obtained the trust of their patients and clients, without which, the MLP would not be able to function. One way that the MLP built trust was by resolving people’s problems. Amy, who initially was very distrustful, said, “once I'd seen that they were helping me and coming – going out of their way I just – after that I completely felt so comfortable with [the pediatrician] I would tell her everything.” In many cases, a relationship between a pediatrician and participants took time to develop. Amy said that after receiving help from her provider, her belief in the provider’s ability to help her increased. She said, “I feel like I expect more from them.”

Many of the participants discussed how the MLP resolved their problems. Some participants encountered providers while they were in crisis, and either had felt that they had no choice or accidentally disclosed their current social conditions. In one case, a participant had been denied school entry for her son due to lack of paperwork, and she was at an impasse. Charlotte said, “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.” Charlotte lacked knowledge that she could access resources, and this coupled with her desire for privacy and independence led to a prolonged absence of school for her son. These external factors were due to a system that does not provide adequate information to parents, and often responds to disclosure with punitive measures. Because she coincidentally had an appointment at a moment where she was in such crisis, she learned “I just have to open my mouth. That's the revelation that I got. If I didn't open my mouth, I never would have known who [the MLP lawyer] or even that woman was. I never would have gotten that far if I had not opened up.” Though accidental, this experience of being vulnerable and sharing her problems with the MLP lawyer was fundamental in Charlotte enrolling her child in school. After telling the lawyer her concerns,
Charlotte accessed critical MLP services for her son. Sara described being in crisis as well when she finally disclosed her situation to her provider. When asked what prompted her to disclose her concerns, she said “I had no choice.” She was in a financial crisis and felt she had no other recourses, and this led her to eventually receiving legal care from the MLP.

These interviews demonstrate the importance of developing an open relationship between patient and provider, and how this relationship is necessary in order to access MLP services. Participants discussed the evolution of this trust, illustrating the role of continuity of care in maintaining these relationships. Another example demonstrates the open relationship between patient and provider. When determining whether to share information with her mental health provider, Charlotte said that “I wanted to get a feel of who she was to see if it was all right. Even for someone I can talk to. If I can talk to you then I'll be okay for my daughter to talk to you. Once I got that from her, I started telling her my story.” Once Charlotte trusted her provider, she was willing to discuss her personal life. When asked what she learned from the experience of working with legal services, Sylvia said that “it's like if I need something or – I'm not going to like be quiet because I know some parents they don't want to deal with them or deal with people, stuff like that. But if I need help I need help. I'm going to ask them.” An integral step in the process of connecting to legal help was disclosing the concern. It was through meeting with the lawyer and finally obtaining help for her son that Charlotte realized 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, so to speak because I was real adamant about that.” Participants needed to feel that they would not be punished or judge when disclosing their concerns. Determining the optimal ways to establish trust needs to be part of any culturally competent intervention that attempts to connect patients to adequate and appropriate legal care through a healthcare setting.
**Building Confidence in Institutions**

As the MLP and connected institutions began to serve participant’s needs, their confidence in those institutions increased. Many of the respondents, once connected to the MLP, began to have more faith that they will receive the services, accommodations, funds, or rights allotted to them. Furthermore, respondents described an increased confidence overall in healthcare, education, and legal institutions even when they received improved care from just one of those.

In addition to trusting that the MLP will help resolve their issues, the respondents described increased confidence in the entire legal system after having worked with the MLP. This related to their general sense that the system functions for them. Nia said that “I have more confidence that, you know, not only are they helpful on their people but they also have your best interest in mind. A lotta times the legal system has your best interest in mind, you know? I have less fear towards that now.” Previously, Nia did not believe that lawyers would advocate for and benefit her. After this experience with the lawyer however, she said that “within legal services in general I feel that now that I have a understanding I wouldn’t feel like it’s a enemy. I feel like more it’s more of a resource.” These quotations demonstrate the long-lasting effects of what occurred when participants had access to adequate and just care. Amy also discussed this, and her perception of lawyers. Previously, she perceived lawyers as “just liars and – you know, because you see what you see on TV.” After having worked with the MLP lawyer, in answer to her perception of the legal system, she said “it changed,” and she understood the lawyer as “just a wonderful person, a helping person.” She grew more confident in and trusting of the legal system.
The respondents also demonstrated a change in how they viewed the healthcare system after they received MLP services. After working with the lawyer to take care of her children’s health as well as other housing concerns, Nia said that “I have more confidence in my healthcare system and I have more confidence in legal system because I know now and I acknowledge and I think I look at people differently now.” Similarly, when asked how she felt after working with the lawyer, Angela responded, “me siento confiada de que del hospital me ayudaron bastante.” (I feel confident that the hospital helped me a lot). Working with the MLP transformed participants from lacking trust in institutions into having faith that sometimes the system will work for them, creating lasting effects on their relationships with the healthcare, legal, and educational systems at large.

**Self-Advocacy**

Interviews also suggested that MLPs can help transform people’s perception of themselves, thinking of themselves as change agents in their own lives, and can lead to an increased self-worth. The interviews demonstrated that participants developed agency and became empowered when working with the MLP to improve their child’s education, housing, health, or general wellbeing. Once they learned about their rights and about the legal process, they asked for what they deserved. For example, when answering what she learned from working with the MLP lawyer, Sherry said: “I learned that everybody has rights. You have rights to things that you – serious things you have rights – she'd tell you what your rights are.” Before working with the lawyer, she was not aware of what she deserved in court. After gaining this knowledge about her rights, she “was prepared when I went to court…and I said what I needed to say.” Working with the MLP benefited her immensely in her legal proceedings.
Another respondent articulated how her access to the legal system had changed. As a result of working with the MLP, she said that “if anything was to arise and it was out of my control, first of all, I know I have resources. I know I can trust the legal system. I know my rights for the legal system.” Working with the MLP lawyer on one topic had drastically shifted her perspective and relationship with the legal system, and now she is “not as afraid of the court system anymore.” Nia described how working with the lawyer let her access the legal system in a novel way. She said that the lawyer “gave me the knowledge that I need and understanding of the legal system so that 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.” Collaborating with the lawyer not only helped her to achieve her goals, but enabled her to become an active actor in the process.

Through the MLP, participants also gained knowledge of the school system, and became empowered to champion themselves. For example, Amy said that the lawyer “made me understand – she actually was teaching me how to act – or what I should say or what I should expect from the school and from out of an IEP.” Amy learned about the services to which she was entitled. She learned that “when I do request anything from school to always have it in writing and to make a copy of it and keep – even if I sent a letter, make a copy and keep it for your own records.” She felt more empowered to demand what her child needed to further his education. After receiving MLP services, she said that now “I have high expectations of them because my daughter is special needs and that's their job. For her aid and stuff like that I do have high expectations for her and I expect that for her to help her learn.” Sequoia similarly learned “don't be intimidated by the school system,” and to work systematically to access services for her child. She said that during a meeting with the school concerning her child’s services, she
“actually sat down and read the whole thing. And I said, ‘Well, wow. I have the right to do this and I have the right to ask for this and I have the right to say 'No' to that.’” Shonda said that she had “learned so much from [the MLP lawyer] as far as the legal aspect, as far as what the school can and cannot do, so maybe one meeting where I was able to go by myself and I knew the terms…There's nothing you can get over on me now because now I know what he's allowed to have and what he's not. And I know what the OHI means and the PPTs and IEPs. I know what all that means. Before, I was lost.” When participants learned about their rights, their relationship with these institutions shifted, and they gained agency within a system that had alienated them and their children. In summary, the lawyer’s guidance and the MLP model transformed how participants interacted with systems and learned how to advocate for themselves and their children.

The MLP led participants to take initiative and become more empowered within institutions that previously had been impenetrable and a source of disenfranchisement in their lives. Participants discussed different scenarios in which they used either the MLP lawyer herself or the lessons she taught them as a resource. After working with the lawyer, participants learned what they were entitled to, and knew that they could contact the attorney as a reliable resource, and a tool to leverage when facing obstacles. Sylvia said that when “something happening, going on with the buses or the school and stuff I can call [the MLP lawyer] and she can call and get them on it.” Accessing a reliable legal resource served as a source of strength and built confidence. When asked what she learned about the process of working with the MLP, Maria said “a veces a que se luche” (sometimes, you have to fight) and “lo hagas todo lo más que puedes, para lograr algo. A veces no es fácil uno poder obtener lo que uno quiere, aun necesitándolo,” (you have to do everything you can do achieve your goal. Sometimes it isn’t
easy to get what you want, but you have to do it). The experience of working with the MLP and developing a more active and trusting relationship with institutions led some participants to realize that they may have to struggle, but the struggle can lead to success. In order to achieve change, participants realized that they need to take agency in the process.

Through the MLP, and establishing trusting relationships with providers, participants were empowered and able to advocate for their children within the healthcare and legal systems. Participants must establish a trusting relationship with their medical provider, however, in order for this empowerment to occur. Participants needed to be able to acknowledge their gap in knowledge to their medical providers, and then the provider must take the time to educate their patient and client. The interviews demonstrated this occurring after overcoming the barrier of mistrust: Amy said that “thanks to [the MLP lawyer] and all the things that she taught me, I think, makes me aware now and I have a more clearer understanding of what is going on with my daughter.” After having worked with the MLP, Amy gained agency within her relationship to the healthcare and legal system. This experience made Amy “feel like I know what to look for. Even though she wasn't supposed to go the ENT something was off with her, so I was like, ‘Let me take her to ENT. Let me call them.’” Sequoia shared a similar sense of empowerment that grew from her relationship with the MLP: “I came a little bit more knowledgeable to how the health care system works, what my insurance covered, what it doesn't cover, what services are out there – now, I know – and what I need from the pediatrician. I kind of tell them what I need from them now.” Sequoia clearly articulated the agency that she gained from working with the MLP, through an increased understanding of her healthcare rights.

MLPs enabled participants to become advocates for themselves even after participants were no longer receiving MLP services. For example, when Charlotte’s son was repeatedly
denied access to his education, Charlotte followed the MLP lawyer’s instructions and obtained the necessary documentation to enroll him. When confronted with an intransigent administration, she challenged it and said “it doesn't matter what you normally don't do. The paper said you must do it or just talk to the person. That's all it takes.” Newly armed with knowledge of her rights, she stood up for herself against a system that was denying her. When the administrator continued to deny her and her child their rights, she said that she “got fed up and finally said how about you talk to my lawyer.” The assurance that she had was due to having her lawyer as a resource – this gave her the confidence to demand what she deserved. After providing legal help and services, the MLP lawyer also taught respondents how to become their own change agents, often through modeling behavior. After receiving legal help, Sylvia learned strategies to access the care she and her children needed, and said that “since I been working with [the MLP lawyer] now that I know she been helping me and now that I know that I was like, well you can do that on your own now. You don't need [the lawyer].” The MLP lawyer facilitated a sense of empowerment and imparted knowledge that helped participants resolve many future issues. She set a precedent of how to act, as in the case of Sequoia: “I'm kind of modeling and mimicking her on my own now and becoming my own advocate and my own spokesperson.” Sequoia followed the lawyer’s actions and manner and in this way, gained confidence in dealing with and navigating institutions: “Moving forward now, I don't even – I think I've had to call [the MLP lawyer] twice this year.” Nia described working with the lawyer and said that “it wasn’t like she was taking over everything, it was more or less, like, ‘Listen, I’m gonna help you help yourself.’” Shonda said that “Everything [the lawyer] 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.” The MLP served as a stepping stone toward more independence and self-advocacy.

Nia summarized how many of the respondents characterized this change in their relationship with institutions. She said that while before she felt stuck, she now knew “that there’s options and I know that you know there’s more than one way to take care of something…I think knowing my rights is what helped me more because if you understand something then you know, you know, what the outcome can turn out to be and you’re more comfortable with it to understand it.” This sentiment demonstrates the power of knowledge – knowing one’s rights opens up resources, institutions, options that were never before accessible. She said that “you have a say so you have a choice, you have voice and I think that’s the main thing that [the lawyer]…established…You have a voice and that’s ‘the main thing. That’s a lot.” Working with the MLP helped these respondents find their voices.

**Finding Community, and the Ripple Effect**

Once trust developed between institutions and participants, and participants received services from the MLP and developed self-advocacy, they then shared this information with their communities and found solidarity. Respondents described initially being overwhelmed with all of the issues that they were facing, which led to a sense of isolation. Working with the MLP lawyer, however, provided people with a sense of solidarity. Nia said that the lawyer “pretty much let me know that I’m not alone in the situation.” Tiana described a website that the lawyer had recommended: “at the bottom of it was a lot of reviews, and I didn't know a lot of people went through the stuff like I was going through.” She had not before known that she was in a community of people who were encountering similar struggles, and had previously “got to the point where I felt like I was alone” before encountering this help.
Working with the MLP had both direct and indirect impacts on others in the community. Many of the participants described how they referred others in their community to the MLP. Charlotte says that she provided the lawyer’s information with a friend, who is now “more interested in getting that same pamphlet from [the lawyer] so she can go down there and see if she can do something herself.” She described another instance of direct referral where she told a friend that “Maybe I can slide you [the lawyer’s] card and introduce you guys. Then you can take it from there.” After referring her friend, she said that the lawyer “wound up pulling through for her as well.” Through this snowball effect, the MLP made changes throughout the community. Amy echoed this inclination to share information, saying “I would definitely pass [the lawyer’s] information along because she’s incredible.” Sequoia also mentioned that she spoke with other mothers whose children were not receiving necessary services, and said that she “referred them to [the lawyer] and I gave them her number and her information.”

In addition to referring friends and family to the MLP, participants described sharing information that they learned with others. Sylvia described the lawyer encouraging her to provide information about Yale’s utility clinics, and said, “I let everybody know. And they go every year because they have it every year.” The MLP lawyer may have only directly helped Sylvia, but this information was disseminated to an entire community. Sequoia described becoming a source of information that led to knowledge acquisition and empowerment within her community. She encountered many challenges while helping her child access education services, and found resources for parents that explain their educational rights. She said “I have a parent handbook rights package and I made a couple of copies of it and I gave it to some moms that never even knew that this handbook exists and the rights that we have as a parent and how we're able to advocate for our children.” The knowledge from the MLP seeped into a community through
working with one client. Sequoia described her experience further and says, “I speak out now for children with autism and mom's learning the red flags early like I did…I encourage moms that I meet throughout the school system to stand firm on what they know or what they think. Don't be intimidated by the school system.” She learned about the healthcare and the legal systems, the services she and her child are entitled to, how to follow-up, and actively worked to share this information with other caregivers. The MLP’s success was not just quantified in the direct service provided, but in the knowledge growth and the agency it generated within this community.

**Discussion**

The findings in this study point to the role of relationships in receiving MLP services through the PCC MLP, and to some of the barriers to establishing those relationships. Specifically, this paper explores the lack of trust between providers and participants and among participants and institutions. Many of the participants described feeling that they could not confide in their providers when asked about their concerns for their child. The participants expressed fear of repercussions, and also described histories of negative and punitive relationships with DCF and other institutions. Participants described the overbearing quantity and type of questions they were asked, as well as the turnover in providers and resident rotation, both of which led to weaker relationships. Another barrier to strong relationships was stigma: respondents discussed not wanting to share information with their medical and legal providers for fear of being judged or potentially found negligent.

Participants also discussed how MLP helped them overcome initial and longstanding distrust with providers, and eventually led to disclosing their concerns to both the medical and legal team. They discussed how working with the MLP fostered trust and confidence in
providers and institutions, which helped lead to their legal successes. They also described how this process led to eventual self-empowerment and self-advocacy with respect to healthcare, legal, and educational institutions. Participants gained a sense of empowerment and promoted change for their children, and they then became change agents within their communities and neighborhoods. They disseminated information into their communities, and encouraged other parents to become advocates and make changes for their children.

Though this research suggests important implications for establishing a successful MLP, some limitations should be noted. Some notable ones involve sampling issues. All the respondents quoted in this paper had successful outcomes after working with the MLP. This clearly omits those who were not able to access MLP services, as well as those for whom the MLP did not lead to a favorable outcome. These voices should be included in future research to gain a better idea of the barriers that are faced when attempting to access legal services. Another limitation is the demographics of those interviewed. All the respondents were women of color. While this is demonstrative of those who were served by the PCC MLP, it would be beneficial to gain insights from other groups of people receiving services in order to investigate the role of gender and race in how people access MLP services.

**Implications**

The overarching implication from this research is the need to establish trust between patient and provider (legal and medical). Without this trust, participants were unwilling to divulge their health-harming legal needs, and thus were not able to access needed care for their children. As mentioned in the introduction, practitioners and policy-makers are increasingly recognizing the role of SDOH in health outcomes, and healthcare providers are creating more interventions and screeners to be able to identify areas of need in their patients’ SDOH. While a
focus on screening patients is clearly important, the sensitivity of these screeners needs to be emphasized. Our findings suggest a need to investigate best practices in how to use these screeners. This study suggests that providers may be using screeners, but participants described not trusting them enough to truthfully answer. In order to effectively screen for SDOH, we must create screeners that will capture information, but we must also consider how and by whom screeners are given. Providers should be trained in how to administer these screeners, as the current format of screening is often perceived as judgmental, which leads to increased stress. Providers ought to be trained in cultural competency in order to provide better care for their patients, and assure their patients of confidentiality, while of course also acknowledging the limits therein. Without adequate training, providers will not be able to provide patient-centered, culturally competent care, which has been proven to lead to improved health outcomes (Nelson, Smedley, & Stith, 2003). Additionally, providers should explain the model and the role of the MLP in the beginning of a patient encounter, similarly to how providers discuss other available services. Advertising the MLP and its benefits in the beginning of a relationship can help facilitate caregivers disclosing potential health-harming legal needs.

An additional barrier between patients and providers that emerged from the interviews was a perceived lack of continuity of care, and this being an impediment in establishing a relationship. This is unavoidable – providers rotate, are sick, change jobs; residents start and end yearly – but this shift can disrupt care to the point that it disrupts building relationships with patients. As a result, patients no longer feel comfortable sharing important health information about their child, and this can act as a barrier to receiving care in an MLP, a reflection borne out by research (Cabana & Jee, 2004). In light of this information, it is important to create systems wherein, as much as possible, patients see the same providers, and when this is not possible,
providers create a warm hand-off system. While an in person warm hand-off may not be feasible in every case, the method can be incorporated into electronic health record systems, with salient information placed at the forefront of the patient’s chart.

Those caregivers who were interviewed for this study point to, both explicitly and implicitly, their history of marginalization from healthcare, legal, educational, and housing institutions. This marginalization is a result of myriad factors, societal and political, economic and historical. This study specifically points to the effects of the participants not knowing to what they are entitled in these domains, and this lack of knowledge leading to poorer outcomes on health-harming legal needs. Considering this, a model must be implemented wherein people are more thoroughly educated on what they are entitled to in all the above domains. MLPs can be an effective method of educating communities on their rights. If people do not know their rights, they cannot advocate for themselves. It is important to investigate the main causes for this knowledge gap, and effective ways to remediate it.
References


