How Trust Impacts Education & Health Care Relationships

Narratives and Recommendations from an Expert Panel of Parents and Grandparents







CHILDREN'S INSTITUTE



"I' m feeling hopeful that by being here, we can spread the word out there so that others can get the help they need."

– Expert Panelist



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Why an Expert Panel?

In 2020 and 2021, Children's Institute, with a focus on improving community partnerships and supports, began exploring blind spots within our structures. We recognized a need for direct, candid input from the families that our programs targeted in order to ensure our services were meeting their needs. For one of our programs, we recruited parents and grandparents as an expert panel to inform us about the strengths and needs of low-income communities in Rochester, NY, with particular attention to the experiences of People of Color. These individuals, we hoped, would guide and expand our understanding of health and education practices and protocols for young children by providing the lived experience that could then help us realign our services in the Rochester community and beyond.



You [CI] expand out for sure and learn more about people's lives. You made the best choice to do this and interact with the people most affected by the programs.
–Expert Panelist

"We are listened to, we are heard and ... all of our opinions are taken into account. ... "
– Expert Panelist

Expert Panel 1.0 (EP 1.0) was convened in late 2021 and met monthly via Zoom into late 2022. Experts in their own lives, their feedback regarding relationships, trust, and their health and education experiences proved invaluable. They weighed in on barriers to access in health and education processes and screenings, technology, language and lexicon, all within the contexts of families, race, power and privilege. Findings were turned into lists of recommendations and checklists that the Expert Panel approved and presented to our organization and project leadership.

One expert told us, "Being part of this panel has... given me a purpose – beyond the kids and everything else that I do. I feel heard, my opinion matters, I feel important." To further our learning and program realigment process, mid 2024 - mid 2025, we invited the Expert Panel (EP 2.0) back again; 4 original members rejoined and 2 more were recruited. Although our goal with the two panels was to improve our own services, we found the information so profound and useful that we wanted to share general recommendations from our experts broadly. We believe the information in this report has the power to improve relationships, trust, and shared decision making across families' health care and educational experiences.

"Being part of this panel has...given me a purpose – beyond the kids and everything else that I do. I feel heard, my opinion matters, I feel important."

– Expert Panelist



Demographics and Methods

The two expert panels comprised seven caregivers: Three mothers; two fathers; and two grandmothers with legal or negotiated custody of their grandchildren. The Experts' children ranged in age from preschoolers to adolescents. All the Experts identify as Black or mixed race, except one who identifies as white with Black, Latino, and Asian children and grandchildren.

Expert Panel 1.0 (EP 1.0) was convened in late 2021 and met monthly via Zoom into late 2022. Panel members were initially asked questions about our Get Ready to GROW comprehensive developmental screening initiative for young children. We quickly found that their input was valuable beyond the GROW project and we began to capture their recommendations to apply more broadly across all CI programs. In 2024, we convened Expert Panel 2.0 (EP 2.0) which ran into mid-2025 and included four initial experts along with two new members. Using a participatory research approach, two EP 2.0 experts served as co-leads who approved and tailored agendas and led sections of meetings. EP 2.0, asked experts to provide guidance and insight on our screening questions and the use of information collected, all with the overarching goal of improving health and education outcomes in communities experiencing disproportionate levels of need. In both EP 1.0 and especially in 2.0, lack of trust in health and education systems resurfaced repeatedly as a primary barrier to the kind of partnerships needed to best support families.

The groups met on Zoom monthly for 75 minutes in the evening. In Expert Panel (EP) 2.0 meetings were preceded by a 30-minute Co-Leaders' meeting to confirm the agenda and prepare activities. Experts participated in ways that worked best for them, which, at times, meant out of cars, while shopping, tending to their children, or on a breaks from work. Meetings and pre-meetings were very well attended. Each Expert was compensated for their attendance at each meeting and the co-leads for EP 2.0 received additional compensation. CI staff communicated with Experts through text, email and occasionally phone calls.

Each meeting began by design with a warm welcome – an open-ended question posed by the facilitator or Expert lead (EP 2.0) and then answered by each participant. Additional questions were then posed, with time allotted for each member to respond. All Expert comments were considered "on topic" and staff did not try to steer the conversation too heavily. Additionally, Experts could and did expand on others' comments and posed questions to staff and to one another. The co-leads during EP 2.0 demonstrated agency by leading through personal stories or prompts, sometimes changing the planned agenda questions. In this way, they set a tone or direction that better matched where they wanted the group to begin; that change often served as the most surprising and illuminating spark to conversation. Meetings ended with an optimistic close – a prompt asking each participant to share something they were taking away from the conversation or thinking about. Each monthly meeting focused on a different topic. The final meeting for each panel allowed panelists to review findings and approve recommendations.

With permission of the Experts in EP 1.0, responses to questions or prompts were transcribed by staff during the meetings; in EP 2.0, because trust was established, we gained permission to use Zoom AI transcription which allowed us to focus on the conversation including non-verbals (e.g., head nodding). At the conclusion of EP 2.0, the project director reviewed and synthesized transcripts, organizing the conversations and responses into core themes through an inductive thematic coding process. Each transcript was read multiple times and representative quotes were grouped under each theme that emerged. The themes were then grouped into larger meta themes in order to create the 4 core themes and eight recommendations included in this report. We then reconvened the panel one more time to share themes and recommendations for input and approval before finalizing this report. Experts weighed in on the findings, photos and look and feel for this report.

We acknowledge that picking and choosing Experts' comments is a form of editorializing. For this reason, while we edited for clarity, length and overlapping thoughts, we made concerted efforts to keep what we believed to be the crux of the Experts' intents. Finally, we have included Appendix A - Experts in Their Own Words, which shares Expert comments in their raw data format grouped by theme to allow their voices to emerge more directly.

Findings – What We Learned

In the following section, we present families' insights thematically. Across two panels that met monthly over the course of two years, we gleaned four primary themes that can drive improvements to programs and services for low-income, Black and Brown families with young children in urban contexts. Each theme includes a narrative synthesis as well as Expert comments to bring each theme to life.

In addition to the thematic insights from Expert comments, we have also included Appendix B which shares our lessons learned as an organization about holding space for family voices and lived experience in our programs. We began this process hoping to get feedback and input from families. We quickly learned that we would have to earn their trust before the Experts would feel confident that Children's Institute was genuinely interested in their perspectives in ways that changed our practices. We include our lessons learned about this process of trust building in an effort to be both transparent about our growth as an organization and to humbly offer recommendations to other organizations that may be at a similar stage of growth to ours.



Trust and Relationships Are Foundational

Families repeatedly emphasized that trust is the prerequisite for effective health and education partnerships. They noted that without trust, developmental screenings, and other data collection processes can feel intrusive and even create fear or uncertainty. For example, one Expert noted, "A lot of parents may not disclose...if that child has been exposed to trauma or traumatic experiences...because, oh, are they going to call child protective." Others said "We don't know why we are filling this out, it's just, you know, a plethora of paperwork," and, "Some people don't want to answer truthfully...like schools, why are they asking these questions? It is that trust right there."

In contrast, when trust is present, families feel that sharing information about their children can become supportive and actionable. One Expert shared a story of how a teacher helped her daughter who was struggling with boundary issues, "Her teacher offered, 'We're gonna spend like about an hour together. We'll do some little games and stuff. Things that will help her, with whatever she's going through.'

"A lot of parents may not disclose...if that child has been exposed to trauma or traumatic experiences...because, oh, are they going to call child protective."
– Expert Panelist

For the whole year. I don't know why but she did it. My daughter grew to love her, you know, like she was her grandma and stuff."

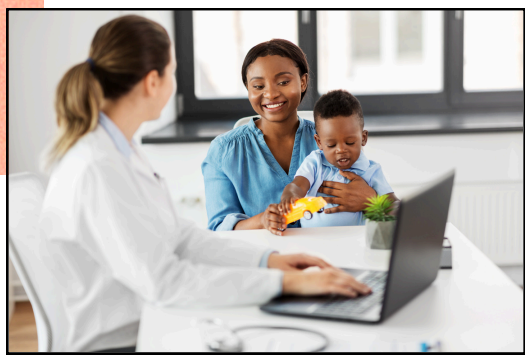
The panelists noted that building trust requires time, consistent communication, and genuine belief in and understanding of families' realities. They noted how important it is for schools to communicate regularly, both when there are problems and when things are going well.



"I want schools to better communicate with me so that we are all on the same page. Even if there isn't a problem."
– Expert Panelist

Systemic Racism and Unequal Treatment Shape Experiences

"I went to the doctor with my daughter [and grandsons] all who are Black. I felt like they were treated differently because of who they are and the color of their skin. We have dealt with a lot of racism in the medical field. I wasn't shocked."
– Expert Panelist



Families described how bias and inequity surface in both schools and health care settings—from harsh discipline for Black and Brown boys to differential treatment in medical settings and surveillance through screening questions. These patterns fuel mistrust and disengagement. In particular, the Experts shared examples of feeling dismissed and judged in health care settings by their providers. One remembered multiple doctors who were "very judgy because I was so young." Another recalled a doctor who "acted like he did not want to be bothered." Examples of racism in the healthcare system included, "I went to the doctor with my daughter [and grandsons] all who are Black. I felt like they were treated differently because of who they are and the color of their skin. We have dealt with a lot of racism in the medical field. I wasn't shocked."

"I felt as if because [my son, when starting in a new school] already had some behavioral issues they kind of... were ready to suspend him...they just went with consequence. You know, they didn't try to actually work it out."
– Expert Panelist

In schools, panel members shared that bias mostly surfaced in the form of suspensions and discipline for behavior challenges. Many Experts felt there was too much emphasis on discipline and compliance and not enough on skill building and identifying the underlying cause of behavior. One shared a story of her son in a new school that communicated he may need to be evaluated after some behavior issues, "So right there, I felt as if because [my son] already had some behavioral issues they kind of...ready to suspend him...they just went with consequence. You know, they didn't try to actually work it out." Others talked about schools overemphasizing compliance and having a quick tendency toward suspension. One shared a story of her grandson, "He stepped on a kid's foot and refused to apologize [so] they suspended him." Another said "the teacher called me every day...with the stupidest issue. 'Oh, he didn't want to stand up today. He didn't want to do this today.' Okay, well, what intervention did you try before that? What happened before hand? Was he upset?"

Educators Have a Lifelong Impact—For Better or Worse



Families shared stories of educators who show care and persistence—calling with good news, solving practical barriers, mentoring, and spending extra time—that were powerful and enduring. Conversely, punitive practices, poor communication, and deficit framing left lasting scars. Many had powerful stories of the educators that made a positive difference in their and their children's lives. In all those cases, the educator focused on getting to know their children and understanding the why behind their behavior. Head Start was singled out for being particularly supportive. One Expert noted, "I would not be so strong without Head Start. Everyone in the building knows me and my son. They make you feel like you are not a number, you are a person." Another said "I had my son young...but Head Start kind of saved me. I needed childcare and they are helping me. They update me on the good days. Once somebody even watched my son at night...It all means so much."

"As soon as I walked in, they acknowledged me [and] my struggle...'I see what you're doing. I see you're trying. I'm not here to discredit you. We're just gonna work together [with your son].'"
– Expert Panelist

In particular, the panel members want educators to recognize their children's and their own strengths, not just their challenges. That helps build trust and a belief that the teachers aim is to truly understand and support their children. One remembered going into her child's school on the defensive but found that, "As soon as I walked in, they acknowledged me [and] my struggle...'I see what you're doing. I see you're trying. I'm not here to discredit you. We're just gonna work together [with your son].'" Another shared how much she appreciated when, "My child had a teacher call home the end of last week who sees the good that [my child] offers to others in their time of need...you know he offered [my child] to be a mentor this year...definitely a great, great thing for him." A third talked about feeling trust for her son's new school "because they actually highlight [his] intelligence as a whole."

"Everyone in the building knows me and my son. They make you feel like you are not a number, you are a person."
– Expert Panelist

Language, Respect, and Belonging Matter

"I'm a great father. I get my son very day. I work at his school. I am everywhere."
– Expert Panelist

Experts were clear that they want to be validated, included and respected as the dedicated parents and caregivers that they are. When asked what people don't know about them, they talked about their dedication to their children: "I dedicated my older years to raising my grandsons. It's not only a second chance for them, but for me too,"; "I love fishing with my kids,"; "I love to bake with them…every Christmas we bang out cookies,"; "I'm a great father. I get my son every day. I work at his school. I am everywhere,"; "I always wanted [my children] to know that regardless of what is going on, my love is unconditional."

They also want healthcare providers and educators to truly see and value their incredible, smart and compassionate children: "My child rings humor and sensitivity – and you don't have a choice but to laugh,"; "Mine are very compassionate. They love people. They will give whatever they have,"; "He will literally put this puzzle together with no picture, nothing…I know he's gonna be like an engineer. Or you know someone important."

Families expressed frustration that providers and educators often make assumptions about who is parenting (e.g. grandparent, same sex couples) and use jargon and exclusive language. They noted how common it is for children to be raised by relatives, family and friends. One said, "They forget in Black and Brown communities we have a village." For example, one of our experts is a grandparent raising two grand-children. She commented, "What grinds my gears is taking my boys to doctor appointments and they call me 'mom.' I am grandma. I clearly look my age. I did not have these kids. I will tell you, 'these are my grandsons…' Until you figure it out, I will tell you."

Others noted that certain terms such as "BIPOC," "pediatrician" vs. [doctor], and "delayed gratification" (from a screening form) did not resonate with them and instead created distance and distrust. Still others wanted schools to create warm inclusive environments. One remembered her son's new school where, "He had no name on his cubby, no name tag on his table, nothing. It wasn't a warm welcome for him." Another suggested that educators should prioritize "comfort over discipline" and should, "Just be nice to [my son]. Talk to him. Let him talk it out. He's a person." Families want to see educators who take the time to truly get to know their children and create environments where they feel safe and valued.

Experts also noted that building trust requires mutual respect, including understanding the practical challenges families face. Several talked about how providing bus passes for medical appointments or to get to school events minimizes the very real challenge of trying to travel by public transportation, particularly in the winter with small children in tow. Some noted that getting to specialists in suburban locations becomes almost impossible because parking and taxi service are prohibitively expensive. Programs that offer rides and validated parking are the most useful to them.

Recommendations

Based on our experiences talking with the Experts over two years and our findings noted above, we offer the following recommendations for healthcare providers and educators to improve services to better meet the needs of Black and Brown families with young children in urban contexts. These recommendations were vetted and approved by the Experts before publishing this report.



"I always wanted [my children] to know that regardless of what is going on, my love is unconditional."
– Expert Panelist

Begin with relationship-building, not forms

Experts suggested that health and education providers start any family interactions with relationship-building rather than procedures like paperwork and policies. Talk to parents and caregivers about their children. Find out what they love about their kids and what strengths they have, their hobbies, and shared interests. Make sure that the environment is inclusive and welcoming with friendly greetings, children's names, and plenty of positive communication.

Create opportunities for shared decision-making and partnership

Ask parents and caregivers how they would like to partner with you as an educator or healthcare provider. For education and health care decisions, lay out the options, clarify and answer questions, talk through pros and cons and ask family members what they think might be best for their child. Collaborate on Individualized Education Plans (IEPs), evaluations for learning disabilities or behavioral concerns, and diagnoses.

Adopt a "Comfort before Discipline" approach

For educators, leading with empathy and calming strategies before consequences is a priority for families. Make an effort to recognize trauma histories, adjust practices, and talk to families to better understand their children's needs. If a child isn't willing to do something, step back, reflect, and try to learn more; punishment should be a last resort, not a primary response.

Apply a strengths-based lens

In communicating with families, observe and highlight children's strengths. To support children's strengths, provide leadership opportunities and, focus on skill-building rather than punishment when it comes to correcting behavior concerns. And always assume positive intent from parents by recognizing and validating logistical challenges (e.g., transportation) without judgement. Above all, practice nonjudgemental listening. It is critical that families feel heard and valued.

Use plain, family-friendly and inclusive language...and do not make assumptions

Always ask how caregivers wish to be addressed and clarify roles. Don't make assumptions and don't tiptoe around families. Just ask questions to clarify (e.g. "How would you like to be addressed?") and build understanding. Until you know, the term "family" is the most inclusive option. Avoid the use of jargon and acronyms.

Explain why you are collecting data and how it will be used

Make it explicit why you are collecting data, how it will be used, and how it will be protected. Simply handing out privacy policies is not enough. Build in relational opportunities to explain forms and procedures so that families feel more connected to their providers and can trust that their and their children's data will be protected. Consider explicitly addressing trauma and fear of repercussions for disclosing it.

Communicate regularly, clearly, and to share good news

Positive communication builds trust; only calling when there's a problem IS a problem. Create opportunities throughout the school year to communicate both challenges and successes. By sharing positive news, families and caregivers will feel more included in their children's educational progress and will have greater trust that the educator sees and values all sides of their child. Make sure to share updates with families when providers, educators or mental health staff change. Predictability and continuity are important for children.

Eliminate Access Barriers

Consider all options for reducing barriers to access. Bus passes may not be the most inclusive option. Where possible consider vouchers for rides and parking validation. Look for other opportunities to make your services more accessible such as evening and weekend appointment times and telemedicine options. Make sure all materials are translated into the languages your families speak. Find out what form of communication (portal, text, email, call) is best for each family and use that when possible.

Conclusion: Honoring Family Wisdom

Families taught us that trust is the work. It is built through everyday acts—warm greetings, positive calls, clear explanations, fair evaluations, and practical supports that acknowledge the realities of caregiving. The recommendations in this report come directly from families' lived experience. We share them in the spirit of partnership and accountability, with gratitude for the Experts who guided us and with a commitment to keep learning alongside the communities we serve.



"I feel like the work we are doing is not done... This work will help and will definitely change the trajectory of kids' lives. But the work will go on!"
– Expert Panelist

Appendix A - Experts in Their Own Words

As noted in the introduction, by synthesizing and summarizing the Expert comments, we conducted a form of editorializing. Although the report was shared with and approved by the Expert panel members before publication, it is possible there are things we missed or meaning we changed through our interpretation. With that in mind, we have included this appendix that captures Expert comments by category without any summary or interpretation. These are the Experts opinions, ideas and recommendations in their own words.

Something people don't often know about the Experts

- I love to read and love to write and I am a freelance writer.
- I do poetry. I write poems.
- I dedicated my older years to raising my grandsons. It not only a second chance for them, but for me too.
- I was born on an army base, and I love math.
- I'm a great father. I get my son every day. I work at his school. I am everywhere.
- Always, even when they were growing up, I always wanted [my children] to know that regardless of what is going on, my love is unconditional.
- Something that is very important to me [as a guardian grandmother] is the boy's mental health. They don't have parents. There will always be that hole. My son is in prison, he has his own demons, but these kids are going to be successful.
- I love fishing with my kids. And letting them take ride bikes.
- I play catch with my son. Whether it's with the football, the baseball, we literally play catch and yeah, he's definitely gotten better.
- I love camping so much and the last time we went was several years ago. But we've got a big camping trip plan for June. I'm so excited... to just go camping, no devices, just go and have a just a great time.
- Any kind of DIY projects, we just do it and cooking, especially baking. I love to bake with them... [and] every Christmas we bang out cookies.
- [I] like to play with the kids... I have so many games it's hard to just pick one.

Myriad strengths their children display

- My kids bring truth and honesty to the table. No matter how painful sometimes it is.
- Technologically, like they are so advanced... They work different devices in technology... that's good because it's something that they can get into career-wise.
- My child brings humor and sensitivity... And you don't have a choice but to laugh...
- And as far as his sensitivity, he's very, very loving... We have a saying... you know, "I love you." And then one says, "I love you more," and then it's, "Never more, always equal."
- Mine are very compassionate. They love people. They will give whatever they have... we've always took care of people... So, they inherited that, that trait.
- Compassion, because sometimes, if we go to the store... my son like, "Here I can give you some of my money," but no, it's okay.
- Being so advanced... we can learn things from them.
- He will literally put this puzzle together with no picture, nothing... I know he's gonna be like an engineer. Or you know someone important.
- I got the X-box running, and I can't figure out how to get my mic to work..."Do this this this and this and this Mom." I'm like 'okay.'

- He's very observing about certain things... especially when it comes into technology and like cars and stuff like that like he paid attention to different types of cars.
- He watches every little thing that I do from the way I walk...good things from me, being nice and sharing... it just keeps me on the right path... because I know that he watches.
- My same son I was talking about, he, he comes to work with me often...He likes helping and, you know, wanting to pass out snacks and wants to help the kids...He's only 4.

What their children notice about the Experts

- Our family has been through you know, some traumatizing stuff. And they notice. You know the sadness you know, and crying.
- My son has noticed that I'm there for him regardless. You know, so I didn't birth him. But I've been in his life from the beginning.
- One thing that my son noticed is that I'm compassionate and caring. Because he's been through a lot. And he knows.

Feelings regarding serving on the Expert Panel

- I'm feeling hopeful that by being here, that we can spread the word out there so that others can get the help they need.
- I joined this for my son. Anything that helps me helps him.
- Being part of this panel has...given me a purpose—beyond the kids and everything else that I do. I feel heard, my opinion matters, I feel important.
- We are listened to, we are heard and that all of our opinions are taken into account. I want to continue to feel important and appreciated.
- I will want for us to get clarity and understanding... and also to give ideas for solutions.
- Coming in here, I thought that I was going to get the services. But I didn't know that you truly were interested in my opinion...
- I was surprised at how open and free we were. Nobody was offended, we could say what we thought. We were just raw.
- I feel like the work we are doing is not done... This work will help and will definitely change the trajectory of kids' lives. But the work will go on!
- You [CI] expand out for sure and learn more about people's lives. You made the best choice to do this and interact with the people most affected by the programs.
- I've always shown up. I've tried to give my honest opinion...
- The sense of community is so important... I just love the way that we can talk frankly about things and you know nobody gets upset. Nobody gets insulted.

How Trust and Relationships Factor into Education

Building relationships between the Experts and schools and childcare centers

- My grandson, when he moved from PreK to "Kindergarten," [the PreK] knew that he did not have parents... So, I voiced that to his [new] teacher and she reaches out to me.
- Being able to have that positive relationship is key. And getting to have the kids together in the same school [next year].
- I want schools to better communicate with me so that we are all on the same page. Even if there isn't a problem.
- I had my son young.... But Head Start kind of saved me. I didn't get DSS so I needed help. A lot. I needed childcare, and they are helping me... They update me on the good days. Once somebody even watched my son at night... It all means so much.
- I would not be so strong without Head Start. Everyone in the building knows me and my son. They make you feel like you are not a number, you are person.
- [Head Start] actually gave me a job to be with my son. I've been there two years with my son. I have great communication with his teacher. I know what he's doing in the classroom.
- My son receives services. I communicate with his teachers and they send home a notebook to let me know what he is doing. He has an IEP and he gets all the services.
- Ever since my children and now my grandchildren, I have had good communication [with the school]. I check their folders every night... So, if there is an issue, I see it.

Stories illustrating how teachers formed relationships and developed trust with Experts

- When I was growing up, I was just more so like a distant person when it came to school... [the teacher] pulled me aside, "Why don't you come?" My mom ended up like struggling... So I realistically told her, like, "I just don't have enough clothes to come to school." [That teacher] went out her way to bring some clothes for me, so, and privately did that. She actually wanted to fix that problem for me.
- For my child, [he] has a speech impediment... when he's not being understood, he tends to act out. I was getting a phone call every day... So I got in the defense mode with this new school... I'm just gonna pull him out... Soon as I walked in, they acknowledged me [and] my struggle... "I see what you're doing. I see you're trying. I'm not here to discredit you. We're just gonna work together [with your son]."
- You know it seems I have my son so young. You know, my education is a blur. Really. I mean, before you knew what, I was in 6th grade, and I'm delivering this boy... Now these boys [grandsons]... Head Start was a turning point... So they were a blessing for my family... [and] getting me involved with Our organization was big.
- My child had a teacher call home the end of last week who sees the good that [my child] offers to others in their time of need, and struggling and whatnot and he, you know he offered [my child] to be a mentor this year... definitely a great, great thing for him.
- My youngest daughter, she had an issue with boundaries. Her teacher offered, "We're gonna spend like about an hour together. We'll do some little games and stuff... You know little socially emotional. Things that'll help her, with her, whatever she's going through..." for the whole year. I don't know why but she did it... my daughter grew to love her, you know, like she was her grandma and stuff.

- In 7th grade, I'm in Cleveland with my mom. And we didn't have really have no family there... I was real smart and stuff... but like I was still kind of in a shell. But there was one teacher specifically... kind of comforted me... "anything I need to help with," or just ensuring me that you know I have other family there... I wasn't alone there... And then I moved back there senior year... she ended up, reaching out to me.

Examples of how Experts gravitate towards educators they trust

- We were doing the whole mental health thing and then the [school] counselor just left. And nobody told us nothing. And it literally, and every time we would call oh you know, the whole run around... And then the parent liaison came into the picture and she definitely eased our minds and hearts about all of that.
- When I first started dealing with special education from my son and that was... long time ago, too. One of the teachers said it seemed like he should be tested for dyslexia. And I said, you know what?... I said, I feel the same way. There's two teachers, one was dyslexic herself... So, they told me... don't let them tell you that there's not a test for dyslexia. It's an auditory processing test, but is for dyslexia. And I said, 'oh, okay, thank you.' You know, the system was giving me a hard time. But I did have those teachers that were helping me.
- There was mistrust in...urban suburban. He [my son] was only there a month... And we were trying to make a behavioral support plan... And then they were communicating to me about maybe he needs to be evaluated... So then right there, I felt as if because [my son] already had some behavioral issues they kind of... ready to suspend him... They just went with consequence. You know, they didn't try to actually work it out. Next meeting... they were trying to throw him into a classroom, a special needs classroom, and if that's what he needs, I don't mind... [but] what did the evaluations say?... I feel more trust with [the urban charter school] that he's going to now because they actually highlight [my son's] intelligence as a whole.
- So [before] I was living in Georgia... I was with my daughter and my son like every day... [after I moved] she would start having behaviors and then [the teachers] they'll ask "what's wrong?" She would say like, all right, [my daughter] is missing her dad... I would still talk to her [my daughter] every day and everything, but... it started affecting her. And, you know, as a kid, it's hard to process that... [the teacher let her] just call me if she's feeling sad or just call [so I could] give her some advice like she was having problems with always wanting to be the line leader...

Stories of Experts' children who were suspended or treated harshly

- It's only been the first month of school and I already had to take [my son] out... because they weren't really approaching the situation appropriately... calling with these situations... Nobody knows nothing... they suspended him based off five-year-olds inputting their thought into what happened. The teacher called me every day after he came back with the stupidest issue. 'Oh, he didn't want to stand up today. He didn't want to do this today.' "Okay, well, what intervention did you try before that? Okay, what happened beforehand? Was he upset?" 'I don't know.' It was constantly that, 'I don't know, I wasn't around,' or never really calling with a positive situation. So, when I call like, "anything happened today? Because you guys call me damn near every day,"... 'Oh yeah, he had a good day.'... "Why nobody reached out to me to say that? But y'all be quick to call me if he didn't stand up or he didn't want to go to story time."

- [My grandson] has mental health issues that he struggles with. My other grandson could do the work, but he'll start working and his [cousin] will snatch his papers... he'll hit him and now [they] are chasing. So, they [the school] wanted to take the field trip from [my one grandson] because he doesn't have his homework done. Now, he's not been sent to the dean's office. He's a good citizen. He's a good student, all of the things, but you want to take the field trip from him. Case management and we're on some wait lists. There's no, no services. Everybody's short staffed. So, there's no skill building. We've been on the wait list now for that for four months. They call for every little thing... He stepped on a kid's foot and refused to apologize [so] they suspended him.
- My son is three years old... just starting Pre—K. The second day of school, he's crying..., "I need to go home. I need to be with my Grammy"... He had no name on his cubby, no name tag on his table, nothing. It wasn't a warm welcome for him.
- My daughter [is] in first grade... sometimes the teacher don't communicate with me and they wait to the last minute when things already occur or happen. So, it's like one time like she was falling behind in certain subjects. And they didn't let me know until like school is like almost over. And I said, well, y'all should have communicated with me more so I would know what was going on and not wait to the last minute... It was towards the end of the school year.
- My grandson got suspended last week... [He] is a reactionary. He's not an instigator...he had been telling us that, you know, a couple of kids was teasing... And so I told him, I said, well, tell your teacher. And so, every time he went to tell. They had some go sit down. ... He goes to tell the lunch aide, "Go sit down and eat your food," you know?... You just get upset with the way that they communicate with the kids. Sometimes there's really something going on. Okay, so he ended up getting into a fight..... I know about dyslexia, okay? He has the same signs. Now... they're trying to classify him as a behavior problem... "we're going to start some testing." So I said, 'Okay, so because it's under behavior, which they always do to our Black and Brown boys, okay, now you're going to test him.'
- My daughter does have a bladder problem... she's very soft spoken too... if she have an accident or something, she won't say it, you know, or she won't come out and say it... it's like a sense of embarrassment... she's not intentionally doing it... We're like trying to figure out why is she having these accidents. Maybe she's playing too much. Maybe she's going to the bathroom too late... But she came to us and she said, "I told my teacher, I have to use the bathroom. She doesn't let me go and not have an accident... I really can't help it." We communicated to the teacher like, 'Hey, you know, we're trying to figure out what's going on now... When she says she has to go, can you please let her?... what's the problem?'... And it's not like she's going to mess around or anything like that... She's a good kid... And it's what the doctor says.

Experts' advice on what educators should do to support their children

- Comfort before discipline.
- I've always been asked how I discipline or how do I reward him? How do I bribe him? And I said, "I don't. I comfort him." And then from there, it'll become a conversation... I've never been asked that [how I comfort him].
- [Educators say] reinforcements and stuff like that, yeah, but never calming.
- Just be nice to him. Talk to him. Let him talk it out. He's a person.
- So I was at [one] school. I was working there part time... What happened with this kid? And he's crying. There was a teacher there... And she went over to him. And she had the most soothing, soothing voice. And she was just talking to him... I don't even remember what she said. But her voice was so comforting, and he was just looking at her head, puddles of water in his eyes. But he was just listening and just the sound of her voice... she was affirming the fact that he was going to be okay.

Insights into Health Care Barriers and Improving Access

Experts' experiences interfacing with health care

- My children went to [a health center]... and now my grandkids. The nurses are nice. And they try to get you in when it is convenient for you.
- Taking my oldest son to [a] health center... there was multiple doctors in there who um who first of all, very judgy because I was so young. And secondly, you know, he's mixed... I ended up switching them out of there. We stayed within the network, but we went to another clinic. And then things were great for him.
- I had a bad experience with a doctor who was not my doctor and he acted like he did not want to be bothered... I was shocked. I reported him.
- For someone with two small kids getting on a bus is hard. It is a task. It is difficult... If I had something besides the bus. Getting insurance to get a taxi, picking you up at your doorstep.
- Don't give me a bus pass because I don't want it. If I need to go to a specialist in the 'burbs, I need a ride. No more bus rides!
- Even if you are driving, that cost for parking [for health care] They should validate parking.
- I went to the doctor with my daughter [and grandsons]—all who are Black. I felt like they were treated differently because of who they are and the color of their skin. We have dealt with a lot of racism in the medical field. I wasn't shocked.
- My children were growing up and [we] went to [a clinic]... My children are mixed and I would get a look. My oldest kids have suffered... I want mixed kids to be treated as the white kids. I have felt it over the years.

Understanding Experts resistance to answering health and education screening questions

- When you present the questionnaire to the parents... and they're like, oh, I just don't have time right now... they're coming up with an excuse, ask them like, what is preventing you from doing the questionnaire? Because you're probably going to get the same answer for a lot of people.
- They're going to lie. They're going to lie.
- We don't know why we're filling this out, it's just, you know, a plethora of paperwork.
- So maybe... if they were done anonymously.
- Make sure that they are in the families home languages.
- I don't know, like, umbrella questions [cause] a lot of parents, anxiety.
- To kind of assist children to get that assistance they may need. So just kind of establishing that trust... we gotta ask these questions.
- Some people don't want to answer truthfully, or some people just rather go straight to their pediatrician. And like schools, why are they asking these questions?.. It is that trust right there.

Other Considerations

How educators or health care providers should address the Experts

- I like family, or "Dear Family". The thing about that is that families are non-conventional now. It feels inclusive. We feel like family. We are all together.
- What grinds my gears is taking my boys to doctor appointments and they call me "Mom". I am grandma. I clearly look my age. I did not have these kids. I will tell you, "these are my grandsons..." Until you figure it out, I will tell you.
- I like family. It is warming and welcoming. Especially for them [the grandmas].
- It could be policy: this is how it should be for written, and voicemails, and this is how you address people in person.
- Do introductions! I always say, "Hi I'm Grandma." That's best.
- It should be on the [educator or health care provider] to do introductions.
- Families are love, and the warmer approach is better.
- "Don't assume, don't tiptoe, just ask." "Don't say 'Are you mom?'"

How trauma and trust affect what families share

- The house fire [and my great-nephew] had never been to school. He's six now, so they just pushed him right to first grade. Right. My sister [who died in the fire] was homeschooling him. Now, clearly she's not. They had a fire drill. He curled up in a ball and lost, he lost his mind... He was so scared. Knowing the backstory of who these children are is going to help... I tried to explain to her [my niece], you know, have a conversation with him and tell him that sound you hear means you pay close attention to your teacher and you follow her directions.
- A lot of parents may not disclose it [family trauma] though. And just ask them in a questionnaire, if the county's not aware or whatever. Parents, if that child has been exposed to trauma or traumatic experiences... may not disclose it because, oh, are they going to call child protective.

Appendix B - Holding Space, Honoring Individuals & Implementing Recommendations Gained through Lived Experience Expertise

Children's Institute recognizes that our staff are likely to have blind spots when it comes to how to best meet the diverse needs of families. To address that and improve our programming, we reached out for insight and wisdom into how to do our work better by learning from individuals and families whose lived experience is underrepresented in our organization. As expected, we learned a tremendous amount from our Experts about how to improve our programming. Perhaps less expected was the knowledge we also gained about what it takes to gather authentic input from the families we hope to support through our programs and services. As part of our own reflective practice, we developed a set of lessons learned on how to better honor and elevate the expertise of those most affected by our work.

So that others who may be in a similar stage of growth can benefit from our experiences, we humbly offer the following regarding: creating welcoming and courageous spaces; learning from and sharing power with individuals; and changing organizational practices based on insight gleaned from Experts in their own lives. These lessons are offered as considerations, not "must-dos." We're still learning, and we share them in the spirit of humility and partnership.

Set the tone before you meet - Trust and clarity start well before the first session.

- Relational "prework" helps. We reached out by phone, text, and email with brief introductions and a clear message: Our role is to learn from your expertise. We heard from our experts that they are often invited to "listen and learn" rather than be listened to; it takes time to reverse that dynamic. Set the stage early and be patient with relationship building.
- Invite enough voices to reduce pressure. Three or more participants helped our group to feel comfortable that no one had to speak unless they were ready. Name explicitly that everyone speaks only for themselves and not their entire identity group.
- Build trust over time. Multiple sessions with the same participants (we found three or more helpful) allow people to feel connected, confident, and competent in a new environment.
- Choose participant friendly logistics. Ask what times work (we found that 6:30 pm on weekdays was best); offer quality childcare when possible; provide virtual options. Cameras can be helpful for connection and authentic participants, and it's also fine when people need to turn them off to care for children or other needs.
- Compensate clearly and promptly. Treat lived experience expertise as professional expertise. We shifted from store gift cards to reloadable credit cards and paid promptly to give participants flexibility.
- Be flexible to accomodate families' busy lives and encourage them to be fully present. (cameras on, not multi-tasking) to respect everyone's time.

Appendix B - Holding Space, Honoring Individuals & Implementing Recommendations Gained through Lived Experience Expertise

Open the Space in the Meeting - We learned that pacing and small rituals matter.

- Don't rush. The Experts reminded us again and again that relationships and trust matter. Leave time for introductions, to co-create shared agreements, and to explain the format. Welcome each person by name at every meeting.
- Start with a warm, neutral prompt. Open ended questions such as "What was something special you liked to do as a kid?" or "What kind of music do you appreciate and why?" helped us to humanize the space. The facilitator can model an answer; anyone can pass.
- Welcome late arrivals kindly. Our Experts were often multi-tasking, coming from work or children's activities, tending to dinner, or managing other obligations. We welcomed each individual when they arrived so they knew they belonged in the space.
- Support shared leadership. Leaders in our group evolved naturally and helped to improve our panel through, at times, changing course. Look for community leadership potential and nurture it. Expect shared leadership to evolve in surprising ways as Experts grow into their roles.
- Co-create "shared agreements". Scribe them and revisit later. These living agreements help name what matters.
- Honor diverse family constellations. The Experts were clear – don't make assumptions; listen and learn how each family defines itself.
- Center a learning stance. We had to constantly check ourselves to make sure that as facilitators and agency representatives, we genuinely believed that our programs could learn from the lived experience Experts were sharing; otherwise, power dynamics reassert themselves.

Meet People Where They Are - Life is complex; flexibility helps keep people connected.

- Normalize real life interruptions. We set aside judgment about lateness, kids on Zoom, eating, cameras off, or answering the phone.
- Offer supports when needed. Where possible, provide additional accommodations to help participants stay engaged.

Navigate Power and Trust - Acknowledging and gently balancing power made conversations more candid.

- Name the power dynamics. We constantly reminded ourselves and the group that this is the Experts' space and we are here to learn.
- Watch confidence grow through resonance. We saw participants deepen insights as they echoed and reinforced one another.
- Document with care. Scribing (de-identified) participant comments became our "gold." We asked permission in advance to share deidentified insights to expand knowledge and inform decisions.
- Be cautious with audio or video recording. Until trust was established—especially with groups that have faced unfair surveillance—we avoided recording. Later, when trust allowed and participants consented, Zoom AI helped our staff attend more closely to nonverbals and group dynamics rather than having to focus on note-taking.

Choose Facilitation Practices That Help - Small choices in listening and format influenced the quality of dialogue.

- Listen more than interpret. We made a concerted effort to ask questions, listen, and check for understanding only when necessary. Nodding can affirm listening—just be mindful not to signal preference for certain comments over others.
- Reflect on our own biases. Before or after sessions, we examined hidden agendas or assumptions that could limit openness to what Experts were conveying.
- Invite all voices. Let those who wish to respond first do so; before moving on, check in with each person to see if they want to add. We found that sometimes quieter folks wouldn't jump in with responses, but when asked if they had anything to add, they shared important and insightful comments.
- Allow organic crosstalk. Some of the richest moments happened when participants spoke to one another, even with overlapping comments.
- Mind the language. At times we slipped into insider acronyms and jargon and learned that made the Experts feel out of place; with time we got better at avoiding those terms and phrases.

Make Sense of Insights and Follow Through - We tried to honor the words themselves and act transparently on what we learned.

- Reread participant comments. We found that letting their words speak for themselves, rather than overlaying professional interpretations, yielded clearer insights. Although we had to do some interpreting to synthesize findings into this report, we have included the In Their own Words Appendix to ensure readers can yield their own learnings from the Experts voices.
- Co-develop recommendations. Draft organizational or programmatic changes based on participant input and bring those back to the group to check for accuracy and to identify what's still missing or needs strengthening.
- Be accountable. Create checklists, make changes based on Expert perspectives, and close the loop so participants know how their time and energy informed decisions.



Making a Difference Together for Children and Families!

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