Policy Brief: Mississippi Thrive! Parent Interviews: Report for Stakeholders

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Background

This study was conducted in the fall of 2020 as part of the Child Health & Development Project: Mississippi Thrive! (MS Thrive), a partnership between the University of Mississippi Medical Center's Children's of Mississippi and Mississippi State University's Social Science Research Center, funded by the Health Resources and Services Administration. The overarching goal of this project was to improve Mississippi's early childhood developmental and behavioral health system, and this study was conducted as one strategy to better understand this system.

The purpose of this study was to gain insight about the experiences parents/caregivers (henceforth "caregivers") of young children (birth to age five) have with the early developmental health system in Mississippi. A larger telephone survey of Mississippi caregivers of young children (birth to age five) was conducted in 2018, also by the Mississippi Thrive! project, in an effort to better understand the early childhood developmental and behavioral health system in the state of Mississippi. Results of that survey can be accessed here: https://mississippithrive.com/mississippi-thrive-chartbook/. The interviews in this study were conducted to delve deeper into caregiver experiences via qualitative inquiry. Topics covered in the interview guide[1] included families' regular health care routines, experiences with their children's health care providers, use of milestone checklists, familiarity with the concept of Adverse Childhood Experiences, experiences with Early Intervention programs, experiences with care coordination, and other concerns. Given that project staff anticipated potential differences in the experiences of caregivers of children with identified developmental/behavioral concerns and caregivers of children without identified concerns, caregivers from each group were recruited.

Recruitment Strategy

Between September and November 2020, a flyer containing key information about the purpose of the interview, inclusion criteria (i.e., a caregiver of a child aged birth to five), and contact information was developed and shared via child-serving organizations and

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[1] This study, IRB-20-309, was reviewed by Mississippi State University's Human Research Protection Program/Institutional Review Board (HRPP/IRB) and has been granted an Exemption Determination.

MS Thrive's newsletter and social media platforms. The flyer also informed potential respondents they would receive a $25 gift card for participating. Project staff were contacted by 29 interested individuals, with 23 completing interviews between September and October 2020.

Sample

Project staff established goals of recruiting 15 caregivers of children without a diagnosed delay and 15 caregivers of children with a diagnosed delay. The eventual sample, which included caregivers of children ranging in age from two months to 5 years, included 15 caregivers of children without and eight caregivers of children with a diagnosed delay for a total sample size of 23. While project staff recruited families statewide, with the support of several agencies, community organizations, and clinics serving young children with special needs, it was difficult to obtain interest from parents of young children with a diagnosed delay who had the time to participate in this study. Many more parents of young children without a diagnosed delay responded to the recruitment efforts. With the exception of one individual, an aunt with guardianship, all respondents identified as mothers to the child of interest.

Results

Well Child Visits

Caregivers were asked to report how often they attended well child visits prior to and following the emergence of COVID-19. With the exception of three children born after the onset of COVID-19, all caregivers reported attending well child visits as scheduled by their primary care provider (PCP). Although all caregivers continued to attend well child visits during the pandemic, their level of apprehension varied. Most of the caregivers reported being comfortable with taking their children to regularly scheduled visits. Some pointed to the care they took individually, as well as the measures adopted by clinics to reduce COVID transmission, as a reason why they were open to attending the visits: "I would take him as long as everything is sanitized and make sure we have our masks on." One concern among caregivers expressing more apprehension was the need for immunization that was not yet available.

> *As far as our regular health care goes, I would say that we don't go in as often. I still call our nurse a lot with questions, but, in general, I would say that I try not take them in as frequently as we used to. But we still get our immunizations and all that.*
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> *Well, I guess you'd say more nerve wrecking than it would be otherwise... Yeah, I brought him for his shots and stuff, and he got an ear infection one time and I brought him then... So, I mean I try and keep him inside, but if he needs something, I definitely bring him.*

One respondent attempted to delay her child's well visit but, upon realizing the COVID-19 issue would not resolve quickly, decided to take her child.

> *In the beginning, before we thought this was going to go on as long as it has, we kind of pushed things out. And then when it just became obvious that Mississippi was failing, we were just like, 'We're just going to have to go to the doctor; we're going to have to continue on.' So, we just made smarter decisions.*

Telehealth

In October 2020, the Centers for Disease Control and Prevention released a report stating that there was a 154% increase in telehealth utilization in the first quarter of 2019 relative to the first quarter of 2020[2]. Respondents were asked whether they had used telehealth for their child and, among those who had, to describe their experience using that modality. Only eight of the 23 respondents reported having a telehealth appointment for their child. They noted several benefits of telehealth appointments. The most cited benefit was the convenience, "… it was good, because I didn't have to leave the house… I liked that better. And it was fast." Another advantage was the ability to shield themselves from COVID-19 and other communicable diseases.

> *Just to have more options and to think about more kids like him with weaker immune systems or conditions such as a tracheotomy to kind of limit their exposure to other people… But even the little things like that that can help.*

One caregiver of a child with identified concerns noted the importance of telehealth when in-person visits are otherwise unavailable by stating, "I liked it because it still gave us an outlet to be able to provide the ABA services." Another respondent believed that telehealth appointments can give providers an opportunity to see the child in their element and to give caregivers feedback.

> *It was good in that we learned, as the parent, more about what to do with him at the house on our own. The therapist got to see the toys that he was playing with at the house on our own and the things that he was doing at home. That gave them a better idea of who he is and what he likes to do. And it gave me a better idea of what to do with him when we were at home.*

Caregivers also experienced challenges with the telehealth approach. The toughest task was keeping their child engaged during the appointment.

> *I think definitely in person is better, and I know a lot of the places are doing everything that they can to keep the kids coming in right now, but teletherapy*

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[2] Koonin LM, Hoots B, Tsang CA, et al. Trends in the Use of Telehealth During the Emergence of the COVID-19 Pandemic — United States, January–March 2020. MMWR Morb Mortal Wkly Rep 2020;69:1595–1599. DOI: http://dx.doi.org/10.15585/mmwr.mm6943a3external icon.

> *was rough… his attention span for that was not the 45 minutes or hour and a half that they would want it to be. So, he was like, 'Peace out, I am done with this.' So, if it is between going in or doing teletherapy, we're going to try and go in if at all possible.*

Caregivers also felt a reduced level of verbal and physical engagement with the provider during telehealth visits.

> *I mean, I like the bedside manner of going into the doctor's office and I'm actually seeing her physically.*
>
> *I feel like face-to-face, if I have an issue, I can point to him or her about it. Or they could take a listen. Or he could illustrate.*
>
> *They weren't able to physically examine the child. Like, look at their ears kind of thing. I did not like that.*

A larger percentage (50%) of caregivers of children with delays reported use of telehealth following the onset of COVID-19 compared to those who provide care to children without delays (25%). This is likely due to differences in reasons for utilizing services. Caregivers of children with delays were using telehealth to continue ongoing therapy services while caregivers of children without delays were using telehealth for sick visits. A common complaint among caregivers of children without delays was the inability to receive a physical exam. These perceived challenges align with reasons for service utilization.

Caregiver-Provider Relationship

A large proportion (18 out of 23) of respondents reported having a pediatrician as their primary care provider (PCP). With few exceptions, caregivers reported having a positive relationship with their PCP. Caregivers commonly described their PCP as possessing a friendly bedside manner. Respondents pointed specifically to PCPs' responsiveness to their questions and concerns, as well as the PCP's ability to offer understandable explanations.

> *They've been just willing to trust my mom gut, you know? … because, you know, the earlier you get started on a lot of this stuff, the better outcomes the child has. Then they were willing to say, 'Okay, let's trust your instinct. You obviously are around [child] more than we are. Let's go ahead and do the next thing.'*
>
> *If I'm concerned about anything, he'll take time and talk to me and he seems to really care about my child and so that's comforting, just knowing they have that care for him. And I like that I can call anytime and ask questions, especially as a first-time parent.*

> *If there is something that they're going to do that I don't understand, she'll sit down and be like, 'Okay.' If she uses a word that I'm unfamiliar with, she'll explain what it is.*

Caregivers also liked it when PCPs playfully interacted with their children.

> *He's very personable. He's a very good doctor, good bedside manner. I like that he interacts with my son a lot and he plays with him. He's kind of energetic. So, he plays with him, and he still entertains him at the same time, even if he's talking to me, he'll be still playing with him.*
>
> *So, it's kind of hard to kind of calm him down because he's so active and he doesn't like being touched, but she gets his attention. She lets him play with her different stuff, like the stethoscope and the thing that looks in your nose and ears, she kind of lets him play with it before she inserts it.*

In addition to showing concern about the child, caregivers noted the attention their PCP paid to their own well-being.

> *Besides caring for my kids and especially [child], she would take the time to see how I'm doing. You know, mentally with everything going on. And I like that too because it's rare that people really want to check in on the parents.*
>
> *Especially having like a special needs child, so she tells me to take a deep breath. She tells me I'm doing a great job. You know, "Keep doing what you're doing." And it's the little things like that that keep you going because she's supposed to be there to care for, you know, my son. She's his doctor, but for her to include me, and my husband, and all of us because there's a family who acts as a unit, and she tries her best to make sure that we're functioning well so that we can take care of him and see him too.*

Caregivers respected PCPs who were willing to admit when an issue extended beyond their expertise.

> *And I like how she informed me that she wasn't as familiar with babies or kids with[specific condition]. So, she's always willing to refer me to this specialist or refer me to, you know, anything that's out of her control, that she feels like she can't properly handle to the level that I want. She has no problems finding me the resources or the help that I need; and I really, really appreciate that about her.*
>
> *She's also not been afraid to say, 'I don't know this. This is outside the realm of my expertise. I think you need to go see such and such doctor or talk to this person,' which I think is great. That's one of the reasons I trust her so much is*

> *because she really has [child's] best interest at heart. She's not trying to preserve her status as a doctor.*

Although not necessarily a specific characteristic of PCPs, caregivers complimented those whose clinics were able to quickly see their children or had evening and weekend hours.

> *What I like most is that if we were to call with him being sick or any questions in the after hours, they get back to us. If they feel like we need to bring them in, they tell you bring him in so they can check him.*
>
> *That they are easily accessible. Also, that the practice in general has after hours and they also have openings on the weekends. I don't feel as stressed on the weekends if they were to get sick, because I know we have that option.*

In a couple of instances, respondents reported having negative experiences with their PCP. In these cases, caregivers perceived the PCP to be dismissive or uninformed about how to deal with children with complex medical issues.

> *A lot of the times [the nurse practitioner is] not there, so we end up seeing actually the doctor, which, I mean, I think it might be time for him to retire, just to be honest with you. Because a lot of things he's missed that I've had to Google and then ask about, and be like, "Well, do you think it's this?" And they're like, 'Oh yeah. Hmm, it's probably that.' So, it's whatever.*
>
> *The pediatricians down here, they're not informed a lot about autism. Any information that I've found out, I've found out on my own will. I go figure it out on my own. But and some of the times, I'm telling them the information… So that's another thing that makes it difficult is the pediatricians, they usually don't know what they're talking about.*

Most caregivers, regardless of their child's health status, had a positive relationship with their PCP. The only concern mentioned by a caregiver of a child without delays was the short amount of time spent with her PCP. For caregivers of children with delays, concerns were centered around the ability to provide care for a child with special needs (n=2).

Milestone Checklists and Developmental Health Promotion

Slightly more than 2/3 (16 out of 23) of respondents reported that their PCP discussed milestone checklists with them. A little more than half (nine out of 16) of these respondents stated they are currently using milestone checklists to track their child's development. Among those who did not receive information about milestone checklists from their PCP, three learned about checklists from other sources (child care providers and a therapist) and are actively using them. Respondents who were not currently using a milestone checklist were not asked to elaborate on their reasons why. The two explanations provided suggest those who did not use a checklist may be skeptical of them. One respondent stated that, "Every baby grows differently, so I follow [milestone checklists] only by so much," while another caregiver said, "It was kind of biased, because no child is exactly where their statistic wants them to be. Every child is different if that makes sense."

Sixteen of the 23 caregivers (slightly more than 2/3) also received information from their PCP about the importance of daily reading, singing, and talking or discussed activities that caregivers could do to support their child's development. Although she had discussed the topic with her PCP, one respondent expressed dissatisfaction with the guidance provided, "So I am an educator and he hasn't as much as I would prefer, but he has mentioned it."

All eight caregivers of children with developmental delays reported discussing milestone checklists with their PCP or other health care provider, while nine of the 15 caregivers of children without delays (60%) reported having discussions about milestone checklists. Despite a higher level of exposure, caregivers of children with developmental delays were less likely to use the milestone checklists on a regular basis. Ten of the fifteen caregivers of children without delays (75%) reported that their PCP provided health promotion guidance (encouraging talking, reading, and singing to young children), compared to 50% among caregivers of children with delays.

Developmental Screening

Slightly less than half (11 out of 23) of respondents reported receiving a developmental screener from their PCP. Two of the 23 caregivers believed that their child would be getting one soon based on their previous experience with an older child or statements made by their PCP at their child's most recent visit.

> *No. Maybe because he hadn't seen him since my son has actually started doing certain motor skills such as walking, talking, using his own hands and stuff to eat, and we haven't seen him in a minute. But I'm sure that they would do that because my oldest son did it.*
>
> *We haven't done one yet. I believe she said that his next appointment we would because he's one now.*

Two of the 23 caregivers reported that their child was screened through other means. One received screening at a public screening event while the second was screened at a therapy clinic.

> *I've never gotten that from the pediatrician, but I have done that with the therapy center… So, they showed me the scores and actually broke it down, what it meant, how it was scored, so I wasn't just looking at numbers and graphs and percentages, and all of that. And I really appreciate that. I like it*

> *when health care professionals are about to help you and actually take the time to, as I say, speak it in plain English.*

Seven out of the eight, or 87.5% of the caregivers of children with delays reported that their child had been screened by their PCP or through another source. Only about 33% (five out of 15) of the caregivers of children without delays reported that their child had received a developmental screening. This suggests that PCPs of typically developing children are largely engaging in surveillance practices rather than consistently conducting formal checks on young children's development.

Adverse Childhood Experiences (ACEs)

Only three of the 23 caregivers reported that their PCP asked about ACEs that their children had experienced. Among the three respondents asked about ACEs, two responses indicated that the PCP discussed stress experienced by the caregiver.

> *His doctor told me that kids often feed of their parents' energy. And they can feel it when the parents are sad.*
>
> *Yeah, so I had [a serious illness] a couple of years ago, and so our son was two. His pediatrician definitely helped us and trying to help him understand what all I was going through and at such a young age. So yes, she did.*

The third respondent indicated the need for her son to be more verbal so that he is able to communicate when he is experiencing stress.

> *Yes. We talk about stuff because he's verbal, but not verbal. Does that make sense? … He can talk, but some of the things he tells you, you're like, 'Huh?' But we went over things to get him better at talking and stuff like that.*

Current Concerns

Ten of the 23 caregivers expressed that they were currently having concerns about their child's development and/or behavior. The most frequently mentioned concern was related to speech delays. Other concerns mentioned by caregivers included school readiness, aggression, and general developmental issues.

Early Intervention Services

Among those indicating that they had current concerns about their child, seven, all of whom had been diagnosed with developmental delays, were receiving services through Early Intervention (EI). The other caregivers reported various reasons why they had not sought EI services, including a need to bring concerns to their PCP, receiving advice not to seek out services, and deciding to wait and continue monitoring their child's development.

> *I think that my son has a speech impediment. We haven't seen him since he started talking, and I need to get him to him so he can be seen.*
>
> *The speech stuff, I was talking to the lady about, she was saying he might grow out of it because I was concerned about his speech, but she said he'll probably grow out of it.*
>
> *So, at her 15-month well-check appointment, I did tell him, what she is not or whatnot, not now, she probably is saying five words yet. And he said he would be happy to put in a referral for a speech evaluation, but he said it was up to me and that we could continue to monitor and check back at her 18 months appointment, which is what I decided to do.*

While several caregivers noted the ease of getting an evaluation through EI, one described the process as challenging based on her geographic location.

> *I guess the hardest thing was between the age of two and waiting on his official diagnosis and knowing that he needed more than speech therapy, but we couldn't get anything until we got his diagnosis. That was difficult because I could tell that he needed something. It was a new world to me, and I had no idea what he needed, so that was difficult, just that waiting process. But it's just part of it, I guess. That is one thing that I will say that was a negative experience as far as trying to get him tested is there is nowhere near us that does any testing, so we had to travel, which I will do any day again if I ever had to. But there aren't very many sites available to get testing, and the lists are crazy long. So, it was a good little while that we were waiting to get him tested for that official diagnosis.*

Recipients of EI services noted both the benefits and challenges of working with EI. With respect to the advantages, several caregivers described the evaluation process as straightforward.

> *It was fairly easy, and I liked the two women that did the testing and how they did it. It was quick and easy. You set your appointment up, you go in there, they explain things to you super thoroughly, they give you a packet with frequently asked questions and all the information and stuff like that. And then, it didn't take long for them to get in contact with me either, to get in contact with me to let me know what was going on with him, if he would need early intervention and stuff like that.*

Once determined in need of services, caregivers felt EI staff were responsive, providing needed services and support for the parent navigating the system.

> *The referral process has been more stressful. We quickly received a referral for occupational therapy with somebody in our area, and that's been great. She's quickly become one of our allies as far as helping us figure out other people we might need to see to unravel all of [child's] health issues.*
>
> *I think they're very vital. They're important. It's convenient too because with the early intervention, not now, but before all the pandemic and stuff, you had them come into your house to work with them. So, it's super convenient.*
>
> *If I had some concerns, they would write them down, then I would sign by that, saying that they wrote it down correctly, showing me that I let them know my concerns. I was able to rate the person coming. Were they prompt, respectful, encouraging, you know, like that?... I actually looked forward to her coming out and actually talking with them.*
>
> *They stayed in communication and like do texts or phone calls, coming out, they would be hands on, even helping me and showing me what I could do and what I could work on. Giving me things like, 'Hey, Mom, whenever you're at Walmart, just buy these blocks. They're only three bucks. If you go to The Dollar Tree, these can help.' They were showing me things around the house. Even though they were there for him, you know, I'm with him 24/7, so they were teaching me tools.*

Caregivers appreciated the tailored approach taken by EI staff and felt the services provided were preparing their child for school success.

> *Oh, it's wonderful, wonderful services....and the reason why I say it's wonderful is because it's preparing him for kindergarten and to be successful in life and he starts regular school I know he's had, he's having the best opportunity, prepare him for kindergarten.*
>
> *Yeah, because they ask questions, they're writing down specific to your child. They're not like walking in and doing the same thing with your child that they're doing with the child before, the child after that. It's specific to him, so that's what I did like about it.*

Caregivers also expressed disappointment about several aspects of EI, most of which was tied to the organization rather than individual case workers. One complaint was the inability to get all needed services through EI.

> *[Child] would qualify for all four of his services under First Steps..., but the only one we were able to get is [specific type of] therapy. Everything else has a wait list. I'm not even sure if [child] is really even on the wait list, considering he's almost three and about to age out of First Steps. I don't speak highly of First*

> *Steps. They're probably doing the best they can. I'm not saying the individual people are at fault, per se. But the process itself is just not very good. I think they're under-funded and under-staffed.*

Another caregiver felt that her child was not receiving services frequently enough to generate improvements.

> *I don't really know if 30 minutes a week is enough, to be honest with you, especially when it's not one-on-one, when there's other kids in a little group, just because you're dealing with multiple children that are delayed and they might have different problems. You know? I don't think that that's right. But I think that's a funding problem, just to be honest with you. I have a degree in education with a minor in special education, but I think that they did well for what was given to them.*

Both pleased and displeased caregivers noted the negative changes that occurred within the program as a result of COVID-19.

> *Like the First Steps, they would come to the home. I have not heard from them since February ... before COVID started... I think there was a new director or something like that. She called to introduce herself to me. And then, in March, she promised that was going to start, virtual, like the telehealth idea, like the little...tests and all of that on my laptop. You know, so I was ready, that was it. I haven't heard from them. Nothing in the mail. I usually see letters in the mail. Nothing. Not even a survey. No email. No phone call. Nothing at all.*

Referral to a Specialist

Among those respondents (11 out of 23) indicating that they had current concerns about their child and/or were receiving services from EI, seven (out of 11) were referred to a specialist. Of the remaining respondents, three (out of four) were told a referral could be provided but opted to decline in favor of further monitoring. One of these four respondents expressed concerns about seeing the specialist but had not discussed the issue further with their PCP. All of the seven caregivers receiving a referral were able to obtain services.

Caregiver-Specialist Relationship

Caregivers had many positive things to report about the quality of care they have received from specialists.

> *There have been several that have been extremely helpful. Way back at the beginning, I guess it was our [specialist], referred us to have a... study done.... We got hooked up with our...therapist. She was the one that really got the ball rolling as far as seeing in the future things [child's] going to need and was actually the one that really encouraged us to apply for the Medicaid disabled*

> *child, which we were approved for, and that has been extremely helpful in paying for all of these things. We were drowning in medical debt for the first year, and I don't think we could have continued much longer paying for the things that he needed without it. She's become a huge advocate for [child], and several others are as well. Overall, I think our providers are excellent.*

Caregivers also pointed to the improvements made by their child as evidence of quality care.

> *He can walk up and down steps now and not feel like he's falling. That's kind of a major thing for a little fella. It's actually so much to the point that the therapist at [clinic] wants to write a letter to the eye doctor down in [city] to get them to look at a couple other things while we're down there next week, because they recognize how much of a difference it made in his ability to just focus on his work.*
>
> *As far as helping him, writing, teaching them how to make straight lines, vertical lines and horizontal line as well, and those physical therapists that he goes to, she's actually helping him. I told her that she's getting him as well. She's teaching him how to kick the ball and walk in a straight line. So yes, definitely the services that he has been getting has been helpful.*

One participant, however, described challenges with respect to the length of time between their referral and treatment initiation.

> *It's just on hold, because he was supposed to go to pre-K and then he got wait-listed, and so we're just kind of like, 'Well...,' you know, because there's nothing we can do. You know, they didn't have enough slots.*

The issue of long wait times also arose in cases when appointments had to be rescheduled.

> *For example, [child] had to miss his...appointment that was in August because I do not take him to appointments if he's showing signs of being sick, whether it's a fever or who knows. You know, I'm just that kind of parent. I do not take him anywhere. So, I had to reschedule that, and she was like, 'Well, you know.' I said, 'I know.' That appointment was supposed to be in August. He won't be able to be seen until April of next year. So, the only time that we can be able to be seen soon is with the pediatrician, if we'd like to come the same day, if not the next day. But as far as neurology, pulmonology, orthopedics, months out. Maybe like six months out, or if we get lucky, five months away.*
>
> *If you have to change your appointments with the developmental pediatrician in [city], you can expect it to be at least two or three months before you will see*

> *them again. I have to call the nurse's line down there, because we had to have the doctor's note to get into one of the therapies and the nurse took care of it for us, but you either go when your appointment is, and if the child's sick or something like that, you can expect it to be another three months before you see that doctor again.*

One respondent described how appreciative she was for specialists who exhibited flexibility with respect to scheduling appointments stating, "Let's say I need an appointment for tomorrow, but she doesn't have anything. She'll call me, 'Hey, I just had this cancellation, is it doable for you?'"

Other issues brought up by caregivers were the lack of follow-up by specialists and the lack of communication and/or contradictory guidance provided by specialists.

> *Nobody has asked me at all since I took her to those first two people. Nobody's asked if I've reached out to anybody else. Nobody's offered to set up another appointment. Nobody's asked if she's speaking, like, nothing.*

> *But you would be so surprised that his specialists, they do not communicate with one another at all… They don't. I've had to put my foot down quite a bit because I was hearing one thing from one specialist and another thing from another one, and it was clashing. And I said, "Hey, I'm not about to be the monkey in the middle here." Well, I mean, they'll say, "Hey, okay. We'll find out." And I'm like, "I know you're not going to do that because he just got out of his procedure, and you have a million other things to do." And the majority of his specialists…,they're actually professors, so I mean, I know you have your students, so I'm not surprised when I have to bring up the same thing several weeks later, and we're back to square one.*

Care Coordination

For both well child and specialty care, there was a general reliance on email and/or phone reminders about upcoming appointments. Comments regarding care coordination suggest that there was coordination of appointments through electronic health records in single health systems but that cross-system coordination is lacking.

> *If I need to see multiple specialists when we drive to [city], they work to try to figure out how to see us all in one day. Generally, as a rule, I see one person here and another person here. It's pretty frustrating because nobody has clinic on the same day at the same time.*

> *I guess it depends…because when you first get started and you're trying to figure out what's going on and you're trying to get into all of those appointments and to figure out what's going on, that's hard. It's hard to make those connections.*

> *I feel like I communicate well with the providers about who's doing what and I make sure that all the things we get from the [clinic] to the different providers, and I make sure I get copies of the IEP [Individualized Education Program], and I take them to the different providers so that everybody knows what everybody's working on.*

Barriers and Facilitators to Health Care

Barriers and facilitators often represent two sides of the same coin. For those caring for children with developmental delays, they are often required to attend multiple appointments during the week. For those without a strong support system or a flexible employer, this presented a challenge.

> *He received [four types of therapy] once a week. We went every week. The barriers to that were simply just fitting it all in as a full-time working parent and having to rely on other people to help me get him there and take time off work.*
>
> *I rely heavily on my mother to get him to a lot of those appointments. She takes him to weekly therapy.*
>
> *I can have my work days changed, but sometimes if the person that's over me is not able to be at work, then I'm next in line, so I can always adjust my schedule when it comes down to my kids.*

Two of the 23 caregivers mentioned reliable transportation and travel distance as barriers to care. Both of these challenges could be addressed through the availability of telehealth and the availability of evening and/or weekend clinic hours.

> *My vehicle went down last year, and I lost my job. So, it was kind of hard to be back and forth, but now I'm back working. I still haven't got a vehicle yet.*
>
> *Now, if they can do more telehealth visits, that'd be good. So, you won't have to actually... like if it was just a well-visit, nothing wrong with them, a telehealth visit could be done instead of having them coming in and doing well-visits and you being among sick people.*
>
> *Having regular office hours outside of the normal, but it's just the sacrifice of taking off of work just for that one time. So, it's not that big a deal, but yes, it was helpful. Our children's pediatrician opened their office for the flu shot after hours, so we didn't have to pay after hours rates or anything like that, but that was super helpful.*

Child Care

Overall, caregivers were pleased with the care their child received from their child care providers. The specific characteristics noted by caregivers as positive included open communication, low student-teacher ratios, flexible hours, and the curriculum. Examples of open communication included actions such as calling to check on a sick child, informing parents about upcoming events, or quickly responding to concerns.

> *They have a thing where we can message the teacher, any time we have a question or a concern, and I love that, and they have a camera where I can watch him, which is nice, you know, he being so little. I like being able to see him.*
>
> *They're good about contacting the parents, getting the parents involved in things, and especially when they have concerns, but they're good about that.*

With respect to the curriculum, six caregivers discussed how their child care centers were preparing children to make successful transitions into elementary school.

> *They do excellent 3K and 4K curriculums, teaching your child letters and numbers and colors and reading early words, preparing them for kindergarten. They really are an amazing preschool. I have nothing but glowing recommendations for them for typical children.*
>
> *I like how they have the classroom set up, as far as the different activities that he'll be learning while he's there. They ask you what are the things that you want him to be worked with while he's in their care. So, they want to help them with what you want them to get down while they're in their care.*

Participants were also comforted by their child's happiness and level of caring exhibited by the child care staff members. Two respondents also mentioned how responsive their child care providers were to parent requests and communications.

> *Well, they are just very nurturing and very loving….They invest in us, we really trust them, and leaving our child with them and know that he's learning and he's getting loved and things like that.*
>
> *I didn't know how he was going to do with new teachers this year because he had just started getting used to his new teacher last year, but he fell right in back to wanting to go to school every day. So, [child care center] has really helped him a lot.*

While 17 caregivers discussed positive aspects of child care experiences, four respondents discussed challenges with child care providers. These included the desire for less sugary food be served and the need to have curriculum available for more advanced children. The caregiver of a child with delays also noted the need for more training for staff.

> *They are very prepared to deal with neurotypical children.... They do a great job with [older child], but we're exploring other options because they don't have the training needed to deal with [child's] issues. They've done as much as they can as far as his [equipment].... They do the best they can on helping us with [exercises] and stuff, but that's just not what they do. They're not trained for it.*

In the two most egregious complaints, the caregivers' children were reported to have been hit with a ruler or experienced neglect.

> *Recently, he told me some things that I wish I had known back then. He was telling me how his teacher hit him with the ruler, because I was showing him the ruler and showing him how to measure, and he was saying the teacher would hit him with it when he wouldn't do his work. So, you know, that was a problem.*
>
> *As of right now, I don't have too many options where I can put him, but I will rate that daycare a two... So, I have to settle for what's left because I have to work. So, as soon as I can find something, I'm probably going to get him out of there....My biggest concern is when I pick him up, his nose be snotty if it runs. Or, if he cries, he has dry tears on his face.*

Caregiver Stress

Most (15 of the 23) caregivers reported that they were currently experiencing stress but coping the best that they can.

> *I mean, we're surviving. I'm certainly glad that their child care center is open again. Of course, we were home for about two months when COVID first started in mid-March, and so that balancing, them both at home and me trying to work from home and my husband trying to work from home mostly, but me being the primary caregiver for my part, and balance work and kids, that was definitely a struggle, but now that they're back in consistent and reliable child care and I'm able to work the hours expected of me, I mean, it's always hard to get dinner on the table and baths and everything at the end of the day, but for the most part, we're balancing well.*
>
> *It's hard. I'm not going to say it's anything easy. It is stressful having to work, and you got to come home and see the kids. You got to do things at home too like housework and stuff like that. Yes, it is hard. You have to take care yourself, so it's not an easy task.*

Despite reporting experiences of stress, a little over half (eight of these 15) of the caregivers could identify resources that would be helpful to them aside from relying on family members for support. For those that articulated these, needed resources included help with child care, including extended hours; financial support; and help running errands such as grocery shopping.

Sources of Information and Support

When asked where they commonly turn for support, 18 of the 23 caregivers listed more than one source of support. For example, one participant explained the circumstances under which she would turn to a health care provider for information and when she was comfortable using the Internet.

> *If it's something like how much medicine to give him or something, something like that I need to know, absolutely for sure, I would call a pediatrician, but if it's stuff I'm curious about, like how to help him sleep better and just stuff like that, I just do a lot of Googling, but that's stuff that I know is not medical advice, where it's actually serious, I'm, of course, going to ask the doctor, but I would say it's a combination, depending on what I'm wondering about. You know, normally I just like to read articles and stuff, just kind of see what other parents are going through, but I kind of just compile the information and decide for myself.*

The most commonly cited sources of information and support were largely split between three categories: the Internet/social media, family/friends, and health care providers. When mentioning health care providers as a source of information and support, caregivers often noted the importance of this source for their child's physical health. Sources on the Internet included websites identified using a search engine, chat groups or message boards, and social media groups and pages maintained on platforms, such as Facebook.

> *I do a lot of internet research. I do a lot of internet research, and I'm a part of a billion Facebook autism groups, and so I'm all in the autism groups.*
>
> *I tend to look online, baby websites, and search up questions that I have. So that's pretty much my go-to when I have any type of question.*
>
> *If I'm stressed out and just want to rant stuff, I will, of course, rant to my husband. But I think it depends on what I need. If I need, like, medical advice, I'll ask his doctor, but most the time if I'm stressed, I'll just talk to my husband or my mom whenever I just want to talk to somebody.*
>
> *I was very involved in our church, and so we do seek guidance from them, as well as other parents. I think for me, it's very helpful. We have a group of friends that we all have kids around the same age. And so it's helpful for us to*

> *go to them if you know, we have a question or concern or "Hey, does your kid do this?"*
>
> *If there's any questions I have, if I don't understand something, I'll normally ask primary care.*
>
> *Right now, I'm trying to figure out what's going on with his stomach issues, and I have no idea. I guess I'm going to go back to our pediatrician here.*

Conclusion

In the fall of 2020, interviews were conducted with parents and caregivers of young children (birth to age five), both with and without developmental delays, in Mississippi. These interviews built upon a 2018 survey that asked parents and caregivers of young children in Mississippi whether their children had regular primary care providers and whether they had received information about developmental milestones and screenings from their health care providers. These interviews gave us more information about whether caregivers regularly used developmental milestone checklists and about their experiences during and after formal checks on their child's development (developmental screenings). This information included caregivers' experiences with any referrals to follow-up services as needed and how the COVID-19 pandemic affected these experiences. Study results point to policy recommendations, outlined below.

The interview results showed that, in 2020, about six months after the COVID-19 pandemic began, parents of young children mostly continued to take their children to well child visits in person rather than utilizing telehealth options, although telehealth options were more commonly utilized by caregivers of children with delays.

Most of the parents and caregivers of young children who participated in this project had positive relationships with their children's primary care providers (PCPs) and were given milestone checklists to mark their children's developmental milestones by these PCPs. While all of the caregivers of children with developmental delays reported discussing milestone checklists with their PCPs or other health care providers, just a little over half of the caregivers of children without delays remembered these type of discussions with their health care providers. A little more than half of the caregivers who were given milestone checklists were using them at the time of these interviews. Despite a higher level of exposure, caregivers of children with developmental delays were less likely to use the milestone checklists on a regular basis.

A little more than half of the caregivers interviewed reported that their young child had been given a developmental screening. While almost all of the caregivers of children with delays reported that their child had been screened by their PCP or through another source, about one-third of the caregivers of children without delays reported that their child had received a developmental screening. Most of these screenings were given by the children's PCPs.

Very few of the caregivers who participated in this project remembered their children's PCPs ever talking to them about Adverse Childhood Experiences (ACEs), stressful events that their children may have experienced, and how to mitigate these experiences.

Most of the caregivers who had concerns about their child at the time of the interview had been referred to a specialist. Most of the caregivers reported overall positive experiences with both early intervention programs and specialists as far as the treatment and interventions that their children received, although they did mention long wait times for services, rushed visits, and providers not communicating well with one another.

Most of the caregivers participating in this project were sending their children to child care at the time of the interview, and most reported generally positive experiences with their child care arrangements. A few caregivers reported child care programs not having appropriate resources or training to address their children's special needs.

Many of the caregivers mentioned how stressful it is to balance all of their responsibilities. Most of them reported seeking support and information from multiple sources, the most common being social media and other online sources, family members and friends, and their children's health care providers.

The following recommendations are based on these findings:

- Consider ways that telehealth could be more beneficial and engaging for families with young children, particular children with developmental delays, such as providing activity kits ahead of time and/or providing more caregiver coaching rather than direct services to young children.
- Promote developmental milestone checklists widely in places where parents of young children visit (i.e., child care programs, medical clinics), and encourage state medical chapters such as the American Academy of Pediatrics, the Community Health Center Association, the Academy of Family Physicians, the Association of Medical Staff Services, the College of Physicians, the Hospital Association, the Public Health Association, the Rural Health Association, and the Medical Association to promote the distribution of and discussion around these checklists any time young children visit their clinic.
- Examine barriers to health care providers administering developmental screenings to all young children at the ages recommended by the American Academy of Pediatrics (AAP) (nine, 18, and 30 months) or any time there is a concern.[3]

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[3] Centers for Disease Control & Prevention. (February 22, 2021). Developmental Monitoring and Screening for Health Professionals. https://www.cdc.gov/ncbddd/childdevelopment/screening-hcp.html#:~:text=The%20American%20Academy%20of%20Pediatrics%20(AAP)%20recommends%20developmental%20and%20behavioral,30%20months

- Encourage caregivers of young children to request developmental screening at the AAP-recommended intervals or any time there is a concern.
- Require insurance providers to cover AAP-recommended developmental screenings and appropriately reimburse health care providers for conducting the screenings and providing families with the appropriate follow-up care, including referrals and further evaluation.
- Provide information to families on identifying and coping with Adverse Childhood Experiences (ACEs) in health care provider waiting rooms or during the visit. Provide families with information on resources, including mental health support, that can be helpful in mitigating the effects of ACEs.
- Incorporate mental health checks and supports into well child visits through the use of mental health specialists in health care provider offices, support lines such as the University of Mississippi Medical Center's Child Access to Mental Health and Psychiatry (CHAMP), referrals to a care coordination service like Mississippi Families for Kids' Help Me Grow Mississippi, or local mental health specialists who provide services to young children.
- Increase funding for more early intervention and specialist positions in Mississippi so that these positions are competitive and attract more applicants in order to expand the availability of providers to young children and families.
- Include information about providing care to children with special needs, such as that offered by the Mississippi Early Childhood Inclusion Center, in all required child care director training, including where to refer families if child care centers cannot meet their needs.
- Promote resource hubs for caregivers of young children, such as the Help Me Grow Mississippi warmline, the Mississippi Thrive! resource maps (currently funded by the Mississippi Department of Human Services), and the Division of Early Care & Child Development's Resource & Referral centers (also funded by the Mississippi Department of Human Services).

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